

**Mental illness and health-seeking of adults and children: A critical
ethnography of Karamoja, north-eastern Uganda**

By

James Wasike Mangeni Byanasaye

*Dissertation presented for the degree of Doctor of Philosophy in the
Faculty of Arts and Social Sciences at
Stellenbosch University*



Supervisor: Professor Mark Tomlinson
Faculty of Arts and Social Sciences
Department of Psychology

December 2020

Declaration

By submitting this dissertation electronically, I James Wasike Mangeni Byanasaye declare that the entirety of the work contained therein is my own original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Copyright © 2020 Stellenbosch University

All rights reserved

Abstract

In current global mental health debates, the themes of taking cultural issues seriously, and sensitivity to local contexts, predominate. Specifically, there is an emphasis on how embracing the knowledge of lay people's explanatory models (EMs) of mental illness can inform actions that target them. Nomadic pastoralists are among the world's poorest and most marginalised people. However, the question of how they understand mental illness is largely unexamined in the literature. This research examined lay EMs of mental illness and health-seeking in a context of humanitarian crisis in Karamoja, north-eastern Uganda. It also examined what informs lay EMs of mental illness and the decisions to seek (or not to seek) care. Data were collected using six complementary qualitative methods: participant observation, conversations, life history interviews, focus group discussions, key informant interviews and secondary data review. The Karimojong cultural concepts of mental illness described syndromes that closely resemble the diagnostic entities of psychiatry, but there were also significant differences. Psychosis was seen as a complex and multilayered serious mental illness, consisting of three distinct subtypes. The local syndrome, defined as having many thoughts, sadness, worries, and solitude, are core features resembling major depression, but was not seen as a persistent problem and thus was not treated. The local syndrome that resembled psychological trauma was perceived to symbolise widespread and collective suffering. In addition, the local syndromes of epilepsy and intellectual disability were identified but were considered to be childhood mental illnesses. With regard to causation, the Karimojong relied significantly on supernatural and psychosocial explanations of mental illness and less on biological explanations. Psychosis-like syndromes were seen as illnesses caused by the actions of different supernatural agents: God, ancestor spirits, the spirits of dead people/ghosts, curses, and bewitchment. The causes of depressive illness and psychological trauma were considered to be social and contextual factors. Experiences of epilepsy and intellectual disability were believed to be largely supernatural in nature, being similar to the explanations of psychosis. However, epilepsy and intellectual disability were regarded as having a biological aetiology, with mainly genetic and physical factors. In terms of the impact and course of mental illness, the sufferers and their families were said to confront numerous social and health difficulties. These difficulties mainly involved being confronted with negative societal attitudes exemplified in stigmatisation and discrimination, as well as dispossession or loss of resources. Moreover, these experiences commonly affected those with conditions thought to be incurable and associated with severe impairment in

functioning, namely psychosis, epilepsy and intellectual disability. Treatment of the different syndromes depended on what was regarded as the cause. For psychosis-like syndromes, the Karimojong relied on indigenous therapy because it was considered culturally appropriate for illness of spirits. Bio-medical care was not sought because it was thought to be neither a cure nor a suitable treatment for “illness of spirits”. In the case of depressive illness, management was primarily psychosocial, involving receiving emotional and social support from relatives, friends, and significant others. The treatment of both epilepsy and intellectual disability was also predominantly traditional therapy, but in a few cases the families of affected children sought bio-medical care. This study is the first of its kind to make an important contribution to understanding mental health issues among nomadic pastoralists in Uganda. It particularly reveals how this marginalised population articulates issues regarding mental health and well-being. In this regard, this study is of critical public health significance. It is not only of mental health relevance but also assists in revealing the broader socio-economic and political issues that impact well-being in Karamoja. Consequently, it provides important insights that can inform the design of culturally sensitive and contextually appropriate mental health interventions for the Karimojong and similar populations in Uganda.

Opsomming

In huidige globale debatte oor geestesgesondheid oorheers die temas om kulturele kwessies ernstig op te neem en sensitiwiteit vir plaaslike kontekste. Daar word spesifiek klem gelê op hoe die kennis van leekmense se verklarende modelle (VM) van geestesongesteldheid omhels kan word om die aksies wat hulle teiken in te lig. Nomadiese veeboere is van die armste en mees gemarginaliseerde mense ter wêreld. Die vraag hoe hulle geestesongesteldheid verstaan, is egter grootliks onondersoek in die literatuur. In hierdie navorsing is ondersoek gelê na VM's vir geestesongesteldheid en gesondheidsoeking in 'n konteks van humanitêre krisis in Karamoja, Noordoos-Uganda. Daar is ook ondersoek ingestel na wat die VM's oor geestesongesteldhede inlig en die besluite om sorg te kry (of nie). Data is versamel met behulp van ses aanvullende kwalitatiewe metodes: waarneming van deelnemers, gesprekke, lewensgeskiedenisonderhoude, fokusgroepbesprekings, sleutel-informantonderhoude en sekondêre dataherziening. Die Karimojong-kulturele konsepte van geestesongesteldhede het syndrome beskryf wat baie ooreenstem met die diagnostiese entiteite van psigiatrie, maar daar was ook beduidende verskille. Psigose is gesien as 'n ingewikkelde en meervoudige ernstige geestesongesteldheid, bestaande uit drie verskillende subtypes. Die plaaslike sindroom, wat gedefinieer word as baie gedagtes, hartseer, bekommernisse en eensaamheid, is kerneienskappe wat soos ernstige depressie blyk, maar is nie as 'n aanhoudende probleem gesien nie en word daarom nie behandel nie. Die plaaslike sindroom wat soortgelyk het aan sielkundige trauma word gesien as simbolisering van wydverspreide en kollektiewe lyding. Daarbenewens is die plaaslike sindrome van epilepsie en intellektuele gestremdheid geïdentifiseer, maar dit word as geestesiektes van die kinderjare beskou. Wat oorsaaklikheid betref, vertrou die Karimojong op bonatuurlike en psigososiale verklarings van geestesongesteldheid en minder op biologiese verklarings. Psigose-agtige sindrome word gesien as siektes wat veroorsaak word deur die optrede van verskillende bonatuurlike middels: God, voorvadergeeste, geeste van dooie mense / spoke, vloeke en betowering. Die oorsake van depressiewe siekte en sielkundige trauma word as sosiale en kontekstuele faktore beskou. Daar is geglo dat ervarings van epilepsie en intellektueel gestremdheid grotendeels bonatuurlik van aard was, soortgelyk aan die verklarings van psigose. Epilepsie en intellektuele gestremdheid word egter beskou as 'n biologiese etiologie, met hoofsaaklik genetiese en fisiese faktore. Wat die impak en verloop van geestesongesteldheid betref, word daar gesê dat die lyers en hul gesinne talle sosiale en gesondheidsprobleme ervaar. Hierdie probleme het hoofsaaklik te make gehad met negatiewe samelewingshouding wat in

stigmatisering en diskriminasie getoon word, asook die onteining of verlies van hulpbronne. Daarbenewens het hierdie ervarings gewoonlik diegene beïnvloed met toestande wat beskou word as ongeneeslik en wat verband hou met ernstige funksionele inkorting, naamlik psigose, epilepsie en verstandelike gestremdheid. Die behandeling van die verskillende sindrome hang af van wat as die oorsaak beskou is. Vir psigose-agtige sindrome het die Karimojong op inheemse terapie staatgemaak omdat dit kultureel geskik was vir die siekte van geeste. Daar word nie na biomediese sorg gesoek nie, omdat daar nie gedink is dat dit 'n genesing of 'n geskikte behandeling vir “siekte van geeste” was nie. In die geval van depressiewe siekte, was die bestuur hoofsaaklik psigososiaal en het hulle emosionele en sosiale ondersteuning ontvang van familieleden, vriende en ander belangrike persone. Die behandeling van epilepsie asook intellektuele gestremdheid was hoofsaaklik tradisionele terapie, maar in enkele gevalle het die families van die geaffekteerde kinders biomediese sorg gesoek. Hierdie studie is die eerste in sy soort wat 'n belangrike bydrae lewer tot die verstaan van geestesgesondheidskwessies onder nomadiese veeboere in Uganda. Dit onthul veral hoe hierdie gemarginaliseerde bevolking kwessies rakende geestesgesondheid en welstand artikuleer. In hierdie opsig is hierdie studie van kritieke belang vir openbare gesondheid. Dit is nie net relevant vir geestesgesondheid nie, maar dit help ook om die breër sosio-ekonomiese en politieke kwessies wat die welstand in Karamoja beïnvloed, te onthul. Gevolglik bied dit belangrike insigte wat die ontwerp van kultuursensitiewe en kontekstueel-toepaslike geestesgesondheidsintervensies vir die Karimojong en soortgelyke bevolkings in Uganda kan inlig.

Acknowledgements

The successful completion of this doctoral thesis gives me a great feeling of pleasure and relief for which I acknowledge the support and inspiration of several individuals and various institutions. I express my sincere gratitude to the Faculty of Arts and Social Sciences, Stellenbosch University for the award of a three year full-time doctoral scholarship that enabled me to take up doctoral training at Stellenbosch University. The Department of Psychology at Stellenbosch University was a wonderful place to study cultural psychiatry. I had an excellent and supportive home for doctoral training.

I would like to thank the Vice-Chancellor, Makerere University, for granting me study leave and additional funding to complete my doctoral studies. I also want to thank the Chair, Department of Sociology and Anthropology, Makerere University, Dr. Mathias Ssamula, and your predecessor, Professor Robert Kabumbuli for the steady institutional support, advice, and personal encouragement you extended to me at various times. Thanks to all of my colleagues at the department for filling in for me for the entire study period.

I am grateful to the Combat of Diseases of Poverty Consortium (CDPC) at the National University of Ireland, Maynooth for the Research training fellowship. Special thanks to: Dr. A. Jamie Saris, Dr. Thomas Strong and Dr. Rebecca King O’Riani for easing my stay and training at Maynooth. Funding from the Carnie Corporation New York through the Social Science Research Council (SSRC) — Next Generation in Social Sciences in Africa Program – which supported me for a year of writing. I wish to thank Wills Robertson and colleagues Linn Biorklund and Dimitra Kalogeropoulou of *Médecins Sans Frontières* Uganda for the opportunity to work with you as a Medical anthropologist. This broadened my horizons and perspective on Karamoja and immensely enriched my own work.

I am deeply indebted to my thesis supervisor, Professor Mark Tomlinson for his great expertise, patience, invaluable support and immense encouragement. Professor Tomlinson’s mentoring skills did not only open my eyes to novel and inspiring ways of learning and doing research but also helped me to develop a deep sense of mutuality and confidence. Mark enabled me to acquire knowledge with comprehension as I mastered the requisite skills of critical analysis in current cultural psychology and medical anthropology discourses. I also thank Dr. Rose Richards for the helpful guidance during the write-up.

I extend special thanks to the Karimojong, adults and children, for sharing their stories of hopes and fears of living in a precarious setting. *Akimwamwakinyo Akuj* (God bless you). Chris Columbus Opesen, Gloria Atoo, Lilly Napeyoko and Richard Busaule were superb research associates. And to Simon, a friend departed too soon (RIP) and team, my sincere thanks for your excellent transcription skills and useful clarifications during the analysis and write-up.

To all my friends and doctoral fellows of the 2010 cohort, thanks for the fruitful academic engagement and mutual support. Dominique Makwa and Yunusy Ngumbi, I deeply appreciate your enabling us to have an “experience-near” that of family at Villa Centra.

In a special way, I extend my deepest thanks and love to my wife, Florence and our sons for their infinite support and sacrifice during this project.

Finally, thank you so very much almighty God for the gift of life and excellent health you have granted me. For even during those most ambiguous and trying times such as when my father was critically ill until his passing on, Good Lord, you blessed me with the grace, patience, and courage to soldier on. I remain grateful forever.

Dedication

In grateful and loving memory of my father, William W. Mangeni (RIP)

Table of Contents

Declaration	i
Abstract	ii
Opsomming	iv
Acknowledgements	vi
Dedication	viii
Table of Contents	ix
List of Figures	xiii
List of Tables	xiv
List of Maps	xv
List of Pictures	xvi
List of Acronyms	xvii
Glossary	xviii
Chapter One Introduction	1
1.1. Introduction	1
1.2. Background to the study	1
1.3. Thesis layout	3
Chapter Two Literature Review	4
2.1. Introduction	4
2.2. Global mental health and international public health	5
2.2.1. A public health approach	6
2.3. Mental illness: Psychiatric and social conceptualisations	7
2.4. Social determinants of mental illness	11
2.4.1. Somatisation	13
2.4.2. Normalisation	14
2.5. Mental health in conflict and humanitarian settings	15
2.5.1. The lifestyle and culture of pastoralists and state policies	16
2.6. Mental health systems	16
2.6.1. Mental health resources and service delivery in LMICs	17
2.6.2. Health-seeking behaviours and pathways to care	19
2.7. Culture and mental illness in SSA	21
2.7.1. Local ethnopsychiatry	22
2.7.2. Lay EMs of mental illness (1970s – 1990s)	23

2.7.3.	Recent case studies of EMs of mental illness in SSA.....	24
2.7.4.	Culture and mental illness in conflict-affected African settings.....	27
2.7.5.	Uganda	29
2.7.6.	Recent views on local/Ugandan concepts of mental illness	31
2.8.	Pastoralist populations.....	34
2.8.1.	Pastoralist Karamoja	35
2.9.	Summary	37
Chapter Three Methodology		38
3.1.	Introduction	38
3.2.	Theoretical orientation	38
3.2.1.	Bio-medical model.....	39
3.2.2.	The interpretive model	40
3.2.3.	The critical model	41
3.2.4.	The mixed interpretive and critical model	42
3.3.	Research design.....	42
3.3.1.	Selection strategy	43
3.4.	Data Collection.....	49
3.4.1.	Data collectors	50
3.4.2.	Participant observation.....	51
3.4.3.	Focus group discussions (FGDs)	53
3.4.4.	Conversations.....	54
3.4.5.	Life history interviews	55
3.4.6.	In-depth interviews with key informants	56
3.4.7.	Document review	56
3.4.8.	Transcription and translation of interviews	57
3.5.	Data management and analysis	58
3.5.1.	Matrix master sheet.....	59
3.5.2.	Thematic networks analysis.....	64
3.5.3.	Content analysis	65
3.5.4.	Descriptive analysis	66
3.6.	Coding catalogue.....	67
3.7.	Reflexivity.....	68
3.8.	Ethical procedures	72
3.9.	Summary	73

Chapter Four Results.....	74
4.1. Introduction	74
4.2. Description of Research Participants	74
4.2.1. Research participants	74
4.2.2. Life history participants	84
4.2.3. Participants in conversations.....	99
4.2.4. FGD participants	101
4.2.5. Key informants.....	103
4.3. Conceptualisation of Mental Illness in Adults only and Health-seeking behaviour	105
4.3.1. An overview of lay conceptions of mental illness	105
4.3.2. Terminologies of mental illness experienced by adults	110
4.3.3. Manifestations of Mental Illness Experienced by Adults	112
4.3.4. Aetiology of mental illness	118
4.3.5. The impact of mental illness	132
4.3.6. Prognosis of mental illness	138
4.3.7. Health-seeking	139
4.4. Conceptualisation of Mental Illness in Children and Health-seeking behaviour	142
4.4.1. Terminologies of mental illness experienced by children	142
4.4.2. Manifestations of Ngibangibangi and Akirakara	144
4.4.3. Aetiology of Ngibangibangi and Akirakara.....	148
4.4.4. Impact of Ngibangibangi and Akirakara.....	152
4.4.5. Prognosis of Ngibangibangi and Akirakara	156
4.4.6. Health-seeking	157
4.5. Conceptualisation of Mental Illness in both Adults and Children	159
4.5.1. Introduction.....	159
4.5.2. Terminologies of mental illness in both adults and children	159
4.5.3. Manifestations of Akibwal.....	159
4.5.4. Aetiology of Akibwal	161
4.5.5. Impact of Akibwal	164
4.5.6. Prognosis of Akibwal.....	166
Chapter Five Discussion	167
5.1. Introduction	167
5.2. Karamoja: a context of humanitarian crisis.....	167

5.3. Lay Explanatory Models (EMs) of mental illness.....	170
5.3.1. Karimojong cultural concepts of mental illness.....	170
5.3.2. Ideas about causation of mental illness.....	181
5.3.3. Impact and course of mental illness.....	188
5.3.4. Treatment of mental illness.....	195
Chapter Six Conclusion	201
6.1. Introduction	201
6.2. Conclusions	201
6.3. Implications of this study	204
6.3.1. Implications for intervention and practice	204
6.3.2. Implications for future research	207
6.4. Study limitations	207
References.....	209
Appendix 1: Informed Consent Form for (adult) Study Participants	238
Appendix 2: Informed Consent Form for (child) Study Participants	241
Appendix 3: In-depth interview guide (Adults).....	246
Appendix 4: Interview Guide for Children.....	248
Appendix 5: Research clearance #2389	249
Appendix 7: Summary thematic network for conceptualisations of mental illness.....	251
Appendix 8: Detailed Thematic network for lay conceptualisations of mental illness (Perceived psychotic problems)	252
Appendix 9: Thematic network – health-seeking for severe mental illness	253

List of Figures

<i>Figure 1.</i> Interdisciplinary theoretical framework for researching mental illness	4
<i>Figure 2.</i> Descriptive model of fieldwork and data collection processes	67
<i>Figure 3.</i> Conceptual model of lay conceptions of mental illness	107
<i>Figure 4.</i> Thematic synthesis of lay conceptions of mental illness	109

List of Tables

Table 1. Extract of Matrix-Master sheet for analysis of FGD data.....	62
Table 2. Coding catalogue for the research participants	68
Table 3. Description of research participants by data source	75
Table 4. Life history interview participants.....	85
Table 5. Summary description of adult participants in conversations	100
Table 6. Child participants in conversations.....	101
Table 7. Focus group discussion with adult participants	102
Table 8. Child FGD participants	103
Table 9. Summary description of the key informants.....	104

List of Maps

<i>Map 1.</i> Location of the Karamoja region in Uganda	44
<i>Map 2.</i> Location of the Karamoja region and the districts of Kaabong and Moroto in Uganda	45
<i>Map 3.</i> Location of sub-county study sites of Loyoro and Nadunget.....	48

List of Pictures

<i>Picture 1.</i> An aerial view of “big villages” (<i>ngierya</i> /Manyattas) of Karamoja	76
<i>Picture 2.</i> A ground view of “big villages” (<i>ngierya</i> /Manyattas) of Karamoja.....	77
<i>Picture 3.</i> Children keeping watch over their village entrance during the day.....	79
<i>Picture 4.</i> A buffer wall behind the door inside a hut in an <i>ere</i> /Manyatta.....	80
<i>Picture 5.</i> A burnt hut within an <i>ere</i> /Manyatta	81
<i>Picture 6.</i> Researcher’s own experience of crawling out of an <i>ere</i> /Manyatta	82
<i>Picture 7.</i> Unfinished pit latrine structure serving members of an <i>ere</i> /Manyatta in Lokonayon	83

List of Acronyms

CAMH	Child and Adolescent Mental Health
CAOs	Chief Administrative Officers
HICs	High-Income Countries
HSSP	Health Sector Strategic Plan
IDPs	Internally Displaced Persons
KIDDP	Karamoja Integrated Disarmament and Development Programme
LMICs	Low- and Middle-Income countries
LRA	Lord's Resistance Army
MDGs	Millennium Development Goals
MHPSS	Mental Health and Psychosocial support
MoH	Ministry of Health
MoKAs	Ministry of Karamoja Affairs
MSF	Médecins Sans Frontières (Doctors Without Borders)
NHP	National health plan
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
PHC	Primary Healthcare
PTSD	Post-Traumatic Stress Disorder
RAP	Rapid Assessment Procedure
RDCs	Resident District Commissioners
SDGs	Sustainable Development Goals
SSA	sub-Saharan Africa
UNCST	Uganda National Council of Science and Technology
UNLA	Uganda National Liberation Army
UPDF	Uganda People's Defence Forces
WHO	World Health Organization
UNICEF	United Nations Children's Fund

Glossary

Ngakarimojong	English
<i>Ajeele</i>	froth
<i>Akapil/akisub l'thuam</i>	witchcraft/bewitchment
<i>Akibwal</i>	psychological trauma
<i>Akilam/ngilam</i>	curse/curses
<i>Akirakara</i>	epilepsy
<i>Akiriket</i>	sacred assembly for the elders
<i>Akitam</i>	worries
<i>Akiyalolong</i>	“depressive illness”
<i>Akoro</i>	hunger/famine
<i>Akuj</i>	God
<i>Amakuk</i>	traditional stool
<i>Amukat</i>	rubber sandals made out of used car tyres
<i>Amuronot</i>	individual [female] possessed by ancestor spirits
<i>Aosou</i>	wisdom
<i>Apokot</i>	arm bangle
<i>Atapapaa</i>	ancestor spirits
<i>Atikonor</i>	rape
<i>Ebela</i>	walking stick
<i>Edakitar</i>	doctor/hospital
<i>Edeke ka ekuwam</i>	“illness of spirits”/general term for mental illness
<i>Egurigur</i>	violence
<i>Ekasikout/ngikasikou</i>	elder/elders
<i>Ekinyit</i>	“a bird of bad omen”
<i>Ekokwa</i>	informal daily meeting
<i>Ekwap</i>	land
<i>Elekes</i>	malaria
<i>Elomanu/elomana</i>	adultery/adulterous
<i>Emuron/emurok</i>	traditional healer/diviner
<i>Ikwa lounoi</i>	food for work scheme
<i>Ilama/Ilamam</i>	cursing/cursed

<i>Ngadam</i>	brain
<i>Ngatameta</i>	“a lot of thoughts”
<i>Ngibangibangi</i>	“intellectual disability”
<i>Ngicen/ngawuyonito</i>	spirits of dead people/ghosts
<i>Ngikerep/ngicen</i>	a subtype of severe mental illness that is associated with having “spoilt brains”
<i>Ngimasimas/ngimathimathi</i>	a subtype of severe mental illness that is recognised as foolishness or having “unbalanced minds”
<i>Ngiwai wai</i>	a subtype of severe and episodic mental illness, which presents with “confusion”

Chapter One

Introduction

1.1. Introduction

This thesis is based on a critical ethnographic study of mental health issues in rural Karamoja, north-eastern Uganda. During 14 months of intensive fieldwork – from July 2010 to August 2011 – I watched, asked questions, listened, and interpreted lay accounts of mental illness and health-seeking by adults and children in Karamoja. The aim was to contribute to an in-depth understanding of how people living in a setting of severe humanitarian crisis (or development crisis) understand mental illness. In such settings, people are exposed to a wide range of conflict, post-conflict and disasters, and normal services are disrupted or deficient to meet their needs. Thus, they experience high levels of stress which contributes to the risk and severity of mental illness. In Karamoja, there are indeed syndemics of violent conflict, insecurity, extreme poverty, and chronic famine, amongst others. However, their impact on the population's mental health is poorly understood. Such an understanding can contribute useful insights for the design of culturally sensitive and appropriate public health interventions for the Karimojong and similar populations in Uganda (Green, 2008).

1.2. Background to the study

Mental illness, defined as distress that impairs cognitive, emotional, and social functioning, is a serious public health concern globally (Desjarlais, Eistenberg, Good, & Kleinman, 1995; World Health Organization [WHO], 2001; cf. WHO, 2019). It accounts for 28% of non-fatal disease burden (years lived with disability) and 11.7% of total disease burden (disability-adjusted life years) (Vigo et al., 2019; WHO, 2019). Mental illness contributes up to 20% of the illness burden in children and adolescents and it is the leading cause of disability in this population group in all regions of the world (WHO, 2019). Yet, the global mental health situation could be worse given the not so widely recognised co-morbidity of mental illness and physical illnesses (Kilbourne et al., 2018; Liu et al., 2017; Prince, Rahman, Mayston, & Weobong, 2014; Singer, Bulled, Ostrach, & Mendenhall, 2017). In Sub-Saharan Africa (SSA), mental illness accounts for 10% of the disease burden and contributes greatly to disability (Sankoh, Sevalie, & Weston, 2018; Tomlinson et al., 2009). Mental health statistics are poor in Uganda, but the suffering attributable to mental illness is estimated at 35% of the population, which is 13% of the total disease burden (Molodynski, Cusack & Nixon, 2017).

Factors such as insecurity, violence, poverty and physical illness are often cited as both the determinants and consequences of mental illness worldwide. The most affected are poor and marginalised groups (Desjarlais, Eistenberg, Good, & Kleinman, 1995; Lund et al., 2018). These factors not only force people to live in fragmented social structures, but also intensify their susceptibility to mental illness in SSA (Belfer & Saxena, 2006; Hoven et al., 2008; Patel, Flisher, Nikapota, & Malhotra, 2008). In Uganda, the high mental illness burden is linked to a volatile context with a history of bloody conflict, recurrent wars, violence and poverty, including HIV/AIDS (Bolton et al., 2003; Kigozi, Ssebunnya, Kizza, Cooper, & Ndyabangi, 2010; Muhwezi, Okello, Neema, & Musisi, 2008; Ndyabangi, Basangwa, Lutakome, & Mubiru, 2004; Republic of Uganda, 2000).

Globally, the quality of life for people with mental illness is aggravated by poor access to treatment (Chisholm et al., 2016; Jacob & Patel, 2014; Rathod et al., 2017; Saxena, Thornicroft, Knapp, & Whiteford, 2007; Wainberg et al., 2017). The treatment gap is wider in low- and middle-income countries (LMICs), especially in SSA where 90% of mental patients are not treated (Fairburn & Patel, 2014; Jacob & Patel, 2014; Patel, 2009; WHO, 2008). They are also often victims of human rights violations, and stigma (Fernandes, Snape, Beran, & Jacoby, 2011; Jorm et al., 1997; Link & Phelan, 2006; Patel et al., 2018; Rüsch & Corrigan, 2013; Thornicroft, 2007). Mental patients in LMICs, for example, are four times more likely to experience unemployment, and three times more likely to be divorced than other comparable social categories (Allotey & Reidpath, 2007; Chandra, Kommu, & Rudhran, 2012; Fisher, Herrman, Cabral de Mello, & Chandra, 2014). Resource-constrained health systems and patients' poor health-seeking behaviour, among other factors, are linked to the lack of services (Bolton et al., 2014; Duggan, 2013; Fairburn & Patel, 2014). In Uganda, mental healthcare services are insufficient. There is neither an operational policy nor a mental health plan to inform service delivery (Abbo, 2011; Kigozi, Ssebunnya, Kizza, Cooper, & Ndyabangi, 2010; cf. Mugisha et al. 2019).

Cultural understandings form explanatory models (EMs), which refer to people's ideas, beliefs and values of mental illness and preferred therapeutic strategies to ameliorate suffering (Kleinman, 1980; Kleinman & Becker, 2000; Weiss & Somma, 2007). Since they vary cross-culturally, the knowledge and understanding of EMs is crucial to inform public mental health interventions that seek to improve global mental health (Kirmayer & Bhugra,

2009; Kirmayer & Pedersen, 2014; Swartz, 1998). A diversity of EMs of mental illness exist in SSA (Patel, 1995). Yet, to the best of my knowledge nothing is known about nomadic pastoralists, who are the focus of this study, in Karamoja, Uganda.

This study was conducted in Karamoja, a region that is home to 1.37 million nomadic pastoralists.¹ They occupy 27,200 km² of semi-arid land in north-eastern Uganda, bordering South Sudan to the north and Kenya to the east (Uganda Bureau of Statistics [UBOS], 2016; United Nations Population Fund [UNFPA], 2018). As a result, there are recurrent structural stressors: extreme poverty, famine, and on-going raids and inter-border wars (Green, 2008; Krätli, 2010). People suffer frequent epidemics of infectious diseases but lack access to quality healthcare. The co-morbidity of infectious diseases and mental illness is well known (Prince et al., 2014), and contributes to shaping people's EMs of health (Helman, 1994, 2007; Kleinman, 1980). But there is no research on mental health in Karamoja, and particularly on how the experience of structural violence (Rylko-Bauer & Famer, 2016) impacts on people's mental health. Therefore, in this thesis, I examine local conceptions of mental illness and health-seeking among nomadic pastoralists in Karamoja, north-eastern Uganda.

1.3. Thesis layout

This thesis comprises six chapters. Chapter 1 presents the general introduction to the study. Chapter 2 reviews the literature. In Chapter 3, the methodology is discussed. Chapter 4 presents the results, focusing on the description of the research participants and conceptualisations of mental illness. Chapter 5 discusses the results, and Chapter 6 presents the conclusion.

¹ The Karimojong Cluster or the Ateker are the largest group of pastoralists in Uganda, including the Pokot, Bokora, Matheniko, Jie and Dodoth. These groups belong to the Eastern Nilotic people who also populate north-western Kenya and the southern part of South Sudan.

Chapter Two

Literature Review

2.1. Introduction

This chapter presents a review of the literature that informs and shapes the focus of the research. The review covers the following aspects: (a) global mental health (GMH) and international public health, (b) mental illness: psychiatric- and social-conceptualisations, (c) social inequities, poverty and mental health, (d) mental illness in conflict and humanitarian settings, (e) mental health systems: a global outlook, (f) culture and mental illness in SSA, and (g) pastoralist populations. As mental health is a complex and multi-dimensional phenomenon, I have drawn upon the scholarship of various disciplines within medicine and the social sciences. These include medicine, cultural psychology, medical anthropology, and African studies (see Figure 1). I hypothesise that such an interdisciplinary framework can contribute to a better understanding and interpretation of mental health issues. Thus, I identified the following search terms: “mental health” (and “illness”), “global mental health”, “public mental health”, “culture and mental health”, and “explanatory models”. Additionally, I used search terms such as “idioms of distress”, “cultural syndromes”, “somatisation”, “social determinants of mental health”, “mental health systems”, “health-seeking behaviour”, and “mental health in conflict” and “humanitarian settings” to identify and review the literature.

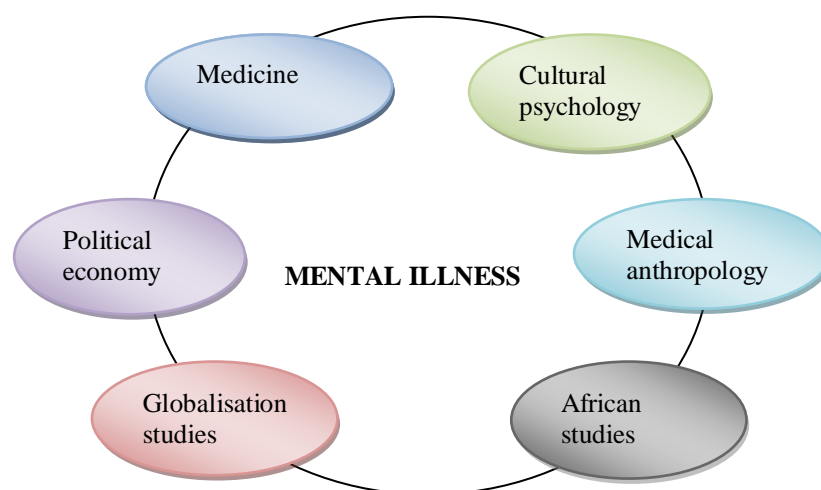


Figure 1. Interdisciplinary theoretical framework for researching mental illness

2.2. Global mental health and international public health

Mental illness has recently gained global recognition as a serious public health concern. This followed the publication of three key documents: the *World Development Report* (1993); the Desjarlais et al. (1995) *World Mental Health Study*, and the Murray and Lopez (1996) *Global Burden of Disease Study* (Dudley, Silove, & Gale, 2012). These studies have shown the enormous health burden caused by mental illness in both high-income countries (HICs) and LMICs (Dudley et al., 2012). In 2001, the World Health Organization launched its WHO Atlas Project. This aimed at compiling and disseminating information on global mental health resources (WHO, 2001).² As a result, it provided the basis for initiatives to mainstream mental health as an international public health issue. Prior to this, mental illness was a largely neglected issue in global health and international public health practice.

Global neglect of mental illness as a public health issue is related to a long and dark history marked by widespread inhuman treatment, extreme fear, and unbearable stigma and discrimination (Becker & Kleinman, 2013; Bedirhan, 1999; Callard et al., 2012; Patel, Kleinman, & Saraceno, 2012; WHO, 2001). People whose behaviour could not be understood, or was seen to be in conflict with societal norms, were thought to disturb public order and pose a danger to others. This was due to a lack of understanding that such behaviours expressed the suffering of mental illness (Callard et al., 2012; Tew, 2011). There was also a fallacy that mental illness was neither real nor curable. Afflicted people were thus not only seen as different but also segregated from the community (Bedirhan, 1999). However, the growing evidence that mental illness is a complex reality that results in loss of human productivity and social functioning has informed new thinking (Golightley, 2008; Kessler, Alonso, Chatterji, & He, 2014). Mental illness is caused by a combination of genetic, biological, social and environmental factors (Patel et al., 2018; WHO, 2001; WHO, 2019). The co-morbidity of physical and mental illness is now recognised, as well as the complex and profoundly negative impact of physical and mental illness on the health of individuals (Liu et al., 2017; Prince et al., 2014).

² In 2001, WHO published the WHO Atlas Project which was updated in the WHO Atlas of 2005, 2014 and 2017. These are the most authoritative and comprehensive sources of information on global mental health resources (WHO, 2011, 2014, 2017).

2.2.1. A public health approach

The shift to a new way of thinking was also informed by the WHO call for a public health approach to mental health. The WHO (2001) pointed out the need to mainstream mental health services in primary care and adopt strategies that promote the rights of patients with mental illness. These include the right to protection and care, non-discrimination of patients, and the patients' right to treatment and care received within community contexts. In addition, patients need to be accorded non-invasive care, provided within the least restrictive environment. In this context, WHO (2001) made several but specific recommendations aimed at strengthening global mental health systems and promoting a public health approach to mental illness. Thus, health systems should (a) provide treatment in primary care, (b) provide care in the community, (c) educate the public, (d) involve communities, families and consumers, and (e) establish national policies, programmes and legislation (WHO, 2001). These issues can be summed up in two ways. First, the need to develop mental health systems based on a human rights perspective. Second, the need to adopt a public health approach that ensures mental health services can access those most in need at the community level.

Despite the change of focus and many gains there were few substantial gains in delivering mental health programmes at a grassroots level (WHO, 2003). In 2003, the WHO responded by developing the Mental Health Gap Action Programme (mhGAP). The mhGAP was mandated to implement prior recommendations by undertaking several global mental health projects and activities. These were: (a) the campaign against epilepsy, (b) suicide prevention, (c) building national capacities to create policies on alcohol use and services, (d) developing guidelines for policy formulation, and (e) improving legislation as well as mental health services (WHO, 2003).

Yet, as it is illustrated in both the *Lancet Series* on Global Mental Health 2007 (Dhanda & Narayan, 2007; Herrman & Swartz, 2007; Horton, 2007; Sartorius, 2007) and 2011 (Eaton et al., 2011; Patel, Boyce, Collins, Saxena, & Horton, 2011; Raviola, Becker, & Farmer, 2011), there is a lack of significant action in addressing the deplorable state of mental health services worldwide. Despite the growing burden of mental illness, services remain either fragmented or non-existent. In most cases, existing services cannot meet the mental health needs of the most deprived social categories globally. This is mainly attributed to diverse barriers, which exist at all levels of the healthcare system that include scarcity of human and financial

resources, and poorly organised services. These views are also reaffirmed by a recent reassessment of the global mental health agenda in the context of sustainable development goals (SDGs). Specifically, it shows that the quality of mental health services remains poor despite the increase in the burden of disease attributable to mental illness, globally (Patel et al., 2018).

2.3. Mental illness: Psychiatric and social conceptualisations

Despite the evidence that mental illness is determined by complex interactions of biological, social and psychological factors (Becker & Kleinman, 2014; Patel, 2014a; WHO, 2001), many approaches focus on a disease model, which assumes that the primary causes of mental illness are genetic and biochemical (Kirmayer, 2006; Saint & White, 2010). Mental illness is thus viewed as resulting from imbalances in genetic and biochemical factors, which in turn interfere with normal human brain functions (Karban, 2011; Lefley, 2010; Swartz, 1998; Szasz, 2011).

The tendency to embrace the disease notion of mental illness has been described as “universalism” or “globalisation” (Bhugra & Mastrogianni, 2004; Summerfield, 2012). Globalisation is used as a synonym for *universalism* to describe how some parts of psychiatry conceptualise physical and mental illness and seek to manage them in *universal* or uniform terms. Thus, for the diagnosis, classification and treatment of mental illness, psychiatry uses standardised tools such as the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and *International Classification of Diseases* (ICD) (Jacob & Patel, 2014; Kirmayer & Swartz, 2014; Patel, 2014b; WHO, 2007b). However, these tools may be limited in terms of their universal acceptability (Becker & Kleinman, 2014; Jacob & Patel, 2014; Jenkins, 1996, 2018; Kirmayer, 2018; Kleinman, 1977, 1988; Summerfield, 2012; Swartz, 2015).

According to Summerfield (2012), psychiatry’s reliance on the use of the DSM and ICD conceptual schemas and related screening tools in cross-cultural contexts has often pathologised social conditions of living. As a result, this has led to the production of what he terms “an epidemic of false positive diagnoses” of mental illness in HICs, particularly Australia, the USA and Germany (Summerfield, 2012, p. 520). According to Summerfield (2012), time trend analyses of public attitudes towards mental illness in these countries reveal an overall rise in biological attributions. For instance, psychoses, such as schizophrenia, and

depression have been increasingly attributed to brain disease, chemical imbalances or genetic causes. Consequently, there has been “a relentless rise in the medicalisation and professionalization of everyday life” (Summerfield, 2012, p. 520).

Likewise, Boyle (2013) argues that, until now, cross-cultural psychiatry endorses a medical view of mental illness. This is exemplified by the application of medicine’s theoretical terms and practices to manage people’s behaviour, thoughts and feelings, based on the assumed similarity between certain behavioural experiences and physical illness. However, psychiatry’s reliance on the medical model to explain certain behavioural experiences as mental illness results in the medicalisation of certain behaviours, and thus the extension of medical authority beyond its limits by the conceptualisation of deviant social behaviours as natural problems that are amenable to medical solutions (Boyle, 2013; Patel et al., 2018; Rose, 2007; Saint & White, 2010). Although the interpretation of behaviours that manifest as mental illness as biological rather than social constructs might remove blame and stigma from the sufferer, this may also exemplify a form of essentialist thinking (Boyle, 2013; Haslam, 2005). This is inconsistent with the understanding that human beings have a range of behaviours whose normality or pathology is constrained within certain socio-cultural niches (Kirmayer & Pedersen, 2014; Saint & White, 2010). Therefore, by locating the primary causes of problematic behaviours and emotions in dysfunctional genetic make-up (biology), medicalisation fails to recognise the relationship between mental illness and social disadvantage.

Both Summerfield (2012) and Boyle (2013) augment Szasz’s (2011) analysis, which asserts that, contrary to the psychiatric claim that mental illnesses are medical diseases, they are products of medicalised behavioural experiences. Moreover, whereas physical diseases are caused by microbes, which can be prevented or cured, mental illness has a contextual aetiology, therefore, such behaviour needs to be understood in the context of the obstacles that people face in everyday life (Szasz, 2011).

Many psychiatric conceptions thus continue to focus on identifying the biological basis of mental illness, and to relate symptoms and behaviours of similar illnesses across cultures (Bock, 1999; Cohen, Patel, & Minas, 2014). This may be possible for disorders like schizophrenia, which have clear dysfunctions of mechanisms that regulate perception,

cognition, and communication (Saint & White, 2010). Nonetheless, there are three major problems with universalism. First, the concept of mental illness derives meaning from an integrated complex of dynamic logics: medical, cultural, socio-economic, spiritual, political and historical (Patel et al., 2018; Summerfield, 2012; cf. WHO, 2001). Second, the issue of interpretation of mental illness goes beyond biological aetiology (Becker & Kleinman, 2014; Kirmayer & Pedersen, 2014; Kirmayer & Swartz, 2014; Lund et al., 2018). Third, depending on the dynamics in Western social, cultural and bio-medical ideologies, psychiatric categories that are used to define mental illness may develop, disappear, or appear over time (Kohrt & Hruschka, 2010; Pilgrim, 2009; Summerfield, 2008).

Compared to “psychiatric universalism” (Summerfield, 2012), social sciences, particularly cultural psychology and medical anthropology, stress the value of social and psychological factors in their understandings of mental illness (Becker & Kleinman, 2014; Carod-Artal & Vázquez-Cabrera, 2007; Kleinman, 1980; Swartz, 2015). From this perspective, mental illness is seen as a phenomenon that results from a “web of causation” (Patel, 1998). This refers to the interaction of several dynamics, including cultural and ecological influences on mental health (Jones, 1994; Lefley, 2010; Wiley & Allen, 2009). Social scientists thus adopt a cultural relativist approach to study illness in a contextualised way. In so doing, they make explicit the meaning of suffering from an emic perspective (Kleinman, 1988; Swartz, 1998). The assumption is that mental illness cannot be understood outside a culture framework. Specifically, the meaning of human behaviour should be interpreted in its specific cultural and social contexts (Kielmann, Cataldo, & Seeley, 2011; Reavley & Jorm, 2011). As such, mental health issues are conceived of as products of the interactions between culture and contextual configurations of society (Brolan et al., 2014; Kirmayer, 2018).

By analysing how variations in economic wealth and political power impact health, cultural relativism distances itself from disease-centred psychiatry and its restrictive focus on pathological causes to a more holistic view of the social construction of the meaning of mental illness (Swartz, 1998; Szasz, 2011). Therefore, adopting a cultural relativist frame helps to unveil the ways in which cultural, socio-economic, political and historical dynamics shape personal experiences of mental illness (Avoke, 2002; Kielmann, Cataldo, & Seeley, 2011). These dynamics are part of a morally constituted system within which behaviour is shaped and defined using cultural notions of health and illness (Good, 1997). In this context,

symptoms and behaviours are interpreted as symbolic communications about mental illness within particular social and cultural contexts (Helman, 1984; Kisanji, 1995; Kleinman, 2009).

Both medical anthropologists and cultural psychiatrists have emphasised that conceptions and understandings of illness, in all its forms, are strongly influenced by social and cultural contexts that produce and shape their experience (Good, 1994; Helman, 1984; Jenkins, 1996; Jones, 1994; Kleinman, 1980). So, even the meanings of biological or physical illnesses are also embedded in social and cultural contexts in which they are experienced. As Helman (1984) argues, the same disease such as tuberculosis or symptom such as pain may be interpreted completely differently by two individuals from different cultures, or social backgrounds, and in different contexts.

In relation to mental illness, however, an overemphasis on cultural relativism may also lead to misconceptions of conditions that have an underlying physical pathology such as dementia. Given its organic origins, dementia may be better understood from a psychiatric standpoint (Karban, 2011). Researchers are thus urged to adopt a (social) realist or critical approach in researching mental illness. This approach recognises the biological reality of certain mental illnesses. It also recognises the social causation of mental illnesses that may not be easily explained bio-medically (Good, 1994; Good, 1997; Kleinman, 1980; Patel, 2014a, 2014b).

Examining the way in which both universalism and relativism describe the reality of mental illness, I think that the strength of one approach might be the pitfall of the other (Becker & Kleinman, 2014; Eriksen & Nielsen, 2001; Lavenda & Schultz, 2008; Patel, 2014a; Tomlinson, Swartz, Kruger, & Gureje, 2007; Swartz, 1996). I thus adopt a pragmatic framework that integrates both theoretical frameworks in a manner that enables me to make the best use of them as they complement and enrich one another. In doing this, I envisage gaining a better understanding and interpretation of mental illness as seen from the Karimojong emic perspective. For, as much as all health problems are linked to socially determined causes, their mediation is ultimately achieved through biological pathways (Lavenda & Schultz, 2008; Patel, 2014a). As Lavenda and Schultz (2008) further note, “human biology makes culture possible; human culture makes human biological survival possible” (Lavenda & Schultz, 2008, p. 7). Accordingly, I agree with Patel (2014a) who argues that it would be naive to stress social causation but ignore the equally critical role of

biological causation of mental illness. I will discuss further the methodological issues underpinning relativism and universalism in section 3.2 of this thesis.

2.4. Social determinants of mental illness

Social determinants, which refers to the conditions in which people are born, grow up, live, work, and age, and the systems put in place to deal with illness, have a significant influence on mental illness³ (Desjarlais et al., 1995; Kleinman, 2000; Lund et al., 2018; Lund, Stansfeld, & De Silva, 2014; Patel & Kleinman, 2003; Scheper-Hughes, 1992). It is demonstrated in these studies that worldwide, social inequities and injustice, particularly extreme poverty, take a huge toll on people's well-being. In particular, the poor suffer deleterious conditions, especially violence, substance abuse, dislocation, the mental health problems of women, young people, and the elderly, including a lack of mental health services. Such conditions perpetrate violence on people as they compromise their ability and right to (mental) health. At stake is, therefore, the need to ensure the poor's civic rights and socio-economic security in order to promote and protect their mental health (Desjarlais et al., 1995; Lund et al., 2018).

While Kleinman (2000) agrees that structural violence shapes social experience by limiting local people's competencies to cope with everyday life demands, he clarifies that structural violence manifests in many ways, which produce social suffering. Social suffering is caused by the "violences" of everyday life, namely high rates of illness and death, unemployment, homelessness and lack of education. It also symbolically presents as extreme poverty, which subdues people to a state of powerlessness and hopelessness, accompanied by shared misery (Kleinman, 2000). For Kleinman (2000), globally, misery manifests in everyday "violences" of hunger, thirst and bodily pain. He reaffirms that structural inequalities perpetuate extreme poverty and associated "violences" of everyday life that produce social suffering. In terms of mental health, structural violence of extreme poverty causes mental illness. For instance, extreme poverty subjects people to depression and suicidal behaviour (Kleinman, 2000).

Social disadvantage and extreme poverty have been consistently associated with increased risk and prevalence of mental illness (Eaton, Muntaner, & Sapag, 2010; Lund et al., 2018; Lund et al., 2014; Perry, 1996). These studies describe a complex and inverse or bidirectional

³Such conditions are in turn shaped by economics, social policies and politics i.e., the ways in which power, money and related resources are distributed in society (WHO, 2008).

relationship between socio-economic status (access to social resources such as power and wealth) and mental health. The alternative explanations for this relationship are the selection/drift and social causation (Eaton, Muntaner, & Sapag, 2010; Perry, 1996). The social causation explanation posits that people of the lowest socio-economic status live in poor social conditions, particularly poverty and violence, which are risk factors for mental illness. Low socio-economic status is thus linked to high mental illness risk (Eaton et al., 2010). On the contrary, the selection/drift account posits mental suffering results in poor socio-economic status. In particular, impairment due to severe mental illness causes deprivation and poverty. Hence, people with mental illness may drift into poverty through becoming unemployed and therefore have low socio-economic status (Eaton, et al., 2010).

A recent systematic review summarises the available evidence regarding the social determinants of mental health and mental illness (Lund et al., 2018).⁴ Lund and colleagues characterise social determinants of mental disorders into proximal and distal factors (cf. Bhugra, Till, & Sartorius, 2013; Lund et al., 2014; Wiley & Allen, 2009). According to Lund et al. (2018), proximal factors include people, objects, or events in the immediate external environment with which the individual interacts that increase or reduce risk of mental disorders. In other words, these factors determine whether one will be predisposed to mental illness or not (Lund et al., 2018; cf. Lund et al., 2014). Conversely, Lund and colleagues conceptualise distal factors as the broader structural arrangements or trends in society which exert their influence on mental disorders in populations. Such factors can impair people's capacity to cope with everyday life stress and lead to mental illness. However, the authors argue that distal factors are frequently mediated by proximal factors. In the final analysis, they demonstrate that mental health and illness are intricately linked and result from complex interactions of proximal (immediate) and distal (ultimate) factors (Lund et al., 2018).

In describing the social causation of mental illness, Patel and Kleinman (2003) show how experiences of poverty and common mental illness (CMDs) intersect in LMICs. Other “social pathologies” or human-made social causes of mental illness include insecurity from war, violence, unemployment and discrimination (Patel & Kleinman, 2003).

⁴ The review sought to develop a conceptual framework for social determinants of mental disorders that is aligned with sustainable development goals (SDGs) (Lund et al., 2018).

In contributing to the discourse linking psychosocial distress to the experience of distressing social conditions – structural violence, Scheper-Hughes (1992) engages with the political economy of maternal suffering and infant mortality in the poverty-stricken shantytowns of Brazil. Infant death and maternal social suffering constitute embodiments of an unjust social order characterised by oppressive power and gender relations. Scheper-Hughes (1992) argues that to understand such embodiment, sensitivity and appreciation of the particular social histories of infant death and localised maternal coping strategies are required. Thus, mothers conceal their social suffering, psychosocial distress or depression through somatisation.

2.4.1. Somatisation

Somatisation refers to illness behaviour where people use idioms of bodily complaints to express both personal (psychological) and interpersonal (social) distress (Igreja, Dias-Lambranca, & Richters, 2008; Kirmayer & Bhugra, 2009; Kirmayer & Sartorius, 2007; Lee, Kleinman, & Kleinman, 2007; Reis, 2013; Swartz, 1998). Somatisation is widely recognised as [illness] behaviour that people exhibit in different parts of the world. But there is lack of theoretical and methodological consensus on why people might somatise. Psychiatric conceptions of somatisation would posit that people somatise to show emotional distress that they cannot articulate otherwise. However, this only partly explains the meaning of somatisation because it does not show how such meaning is informed by, and derives from, the social context in which somatisation occurs (Kirmayer & Bhugra, 2009; Kleinman, 1977).

Moreover, sociosomatic explanations that link adverse life circumstances to physical and emotional illness are common. However, the fear of social stigmatisation may force people to conceal social and emotional distress. Thus, they will express somatic symptoms and illness that may be tolerable to society (Kirmayer & Bhugra, 2009). This calls for a contextualised view as it helps to shift the focus from conceptualising somatoform disorders as a specific category, to interrogating how social context, cognitive and emotional processes shape response to bodily distress (Kirmayer & Bhugra, 2009). By focusing on the ways context shapes health behaviour, the social perspective seeks to establish the motivations for people's somatic behaviour. This perspective thus interprets somatic illness in terms of the complex interactions that people have with society's social structures (Kirmayer, 1984).

In a critical rejoinder to this discourse, Lock (1993) argues that people use somatic complaints to express emotional distress as a means of enacting the sickening social order in society. However, it also reveals the actors' experience of body symptoms and emotional distress. From this viewpoint, Scheper-Hughes and Lock (1987) view somatisation as a metaphor for expressing personal and interpersonal tensions. As Lock (1993) further argues, [illness] somatisation can be seen as a cultural performance of social contradictions in society. Scheper-Hughes (1992) applies this perspective and demonstrates how poor women's somatic behaviours comprise strategies for coping with everyday life demands caused by structural violence in Brazil. Moreover, women's responses to distress involved another subtle strategy of normalisation (Scheper-Hughes, 1992).

2.4.2. Normalisation

Bury (1991) defines normalisation as a form of psychological coping by people who show no evidence of dysfunction despite their experience of distress. For Pierre (2003), people will normalise distress and learn to take it as part of their everyday life if society reprimands and punishes its overt expression. In line with these conceptions, Scheper-Hughes (1992) explains how poor Brazilian women learnt to [*in-*]voluntarily mask their experiences of everyday violence occasioned by a repressive social order. It is argued that in oppressive contexts where distress is deemed criminal and punished, or attracts stigma, people will resort to normalising or depathologising distress (Haslam, 2005). Thus, Scheper-Hughes' (1992) analysis of Brazilian women's lived experience of structural violence augments the empirical relevance of scrutinising how a hegemonic and oppressive social order impacts mental health.

Overall, the above studies enrich our understanding of how psychosocial distress relates to people's experience of dominant and oppressive social structures. In this, they provide useful concepts for the analysis of mental illness and inequities in LMICs, namely structural violence, *violences* of everyday life, social pathologies, social suffering, somatisation and normalisation of distress. Also, there is an emphasis on how contextualisation – situating behaviour within a social context – enhances the understanding of social experience.

Furthermore, these studies show that, while the determinants of mental illness may be similar across contexts, their experience and interpretation tend to vary greatly. Coping depends on socio-demographics, economic conditions, cultural ideologies, and politico-historical contexts (Good, 1997; Lund et al., 2018).

2.5. Mental health in conflict and humanitarian settings

Contexts affected by violent conflict and other disasters (human and non-human) often present as complex emergencies (Jones et al., 2009; Tol et al., 2011; Tol et al., 2013). Complex emergencies are affected by pervasive violence and loss of life, massive human dislocation, and extensive damage to societies and economies, which need multi-level humanitarian assistance (OCHA, 1999, cited in Jones et al., 2009, p. 654). Humanitarian settings refer to a broad range of emergency situations that include a wide range of conflict and natural disasters. As a result of these difficulties, normal services are disrupted or insufficient to meet dislocated people's needs and the national and international agencies that operate in such areas require coordination (Jones et al., 2009; Jordans & Tol; 2013).

In terms of mental health and well-being, populations living in such settings tend to suffer a high prevalence of mental health and psychosocial problems. This is because of exposure to multiple and simultaneously occurring risk factors such as war, armed conflicts, mass displacement, poverty, and systematic marginalisation (Jones et al., 2009; Jordans & Tol, 2013; Venvtevogel, van Ommeren, Schilperoord, & Saxena, 2015). Mental health and psychosocial suffering is thus associated with experience of changes and stressful conditions in which people are forced to live (Kinyanda et al., 2010). Importantly, people with mental health problems, particularly psychosis, may suffer further neglect and vulnerability; they lack the family protection and social support that would enable them to function (Jones et al., 2009; Tol et al., 2011; Venvtevogel et al., 2015). The risk of vulnerability may also increase due to living as refugees and suffering verbal and physical abuses. In addition, while displacement often leads to dispossession, people with mental health problems are the most dispossessed worldwide (Jones, et al., 2009).

A systematic review of mental health and psychosocial well-being in humanitarian settings reveals prioritisation in identification of rates of post-traumatic stress disorder (PTSD) and other CMDs (Tol et al., 2011). However, severe mental illness, especially psychosis, is often ignored despite equally deserving serious attention (Jordans & Tol, 2013; Tol et al., 2011). Therefore, while mental health and psychosocial support (MHPSS) interventions are frequently implemented, they focus mainly on PTSD (Tol et al., 2011). MHPSS interventions also often prioritise people's physiological needs and tend to neglect mental health (Jones et al., 2009; van Ommeren, Morris, & Saxena, 2008; WHO, 2013). The range of dynamics and

social factors that contribute to mental illness risk, as discussed above, are also closely associated with the lifestyle of pastoralists, as illustrated below.

2.5.1. The lifestyle and culture of pastoralists and state policies

Globally, pastoralists live on highly marginal land in the harshest and remotest areas such as deserts, grasslands, savannas, mountains and the arctic tundra. Such regions are either too cold or too arid for cultivation. Besides livelihood threats related to weather vagaries, pastoralists also face many risks and vulnerability due to diseases, pests, lack of infrastructure and violent conflict-related insecurity (Fratkin & Meir, 2005; Peoples & Bailey, 2009; Pike, Straight, Oesterle, Hilton, & Lanyasunya, 2010). More importantly, wherever they live, pastoralists have been exposed to marginalisation and discrimination for generations (Schlee, 2013). Often they are minorities in their home countries living in remote and ecologically hostile areas such as arid lands and resource-scarce contexts where survival is difficult. Such areas are unsuitable for crop farming and the development of infrastructure. Herding livestock thus enables them to meet their basic needs and survive (Peoples & Bailey, 2009; Zinsstag, Ould Tabel, & Craig, 2006).

Globally, formal state policies are often hostile to pastoralists, with policies constructing pastoralism as an outmoded and inefficient means of production (Marchi, 2010). They are also constructed as people who hold on to a conservative culture and traditions and are resistant to change (Marchi, 2010). The policies also emphasise that nomadism hinders the development of social services for pastoralists (Schlee, 2013). But government policies and actions, particularly land alienation and forceful settlement, often disrupt the cultural and economic life of pastoralists (Green, 2008; Marchi, 2010). As a result, pastoralists suffer intra-community and inter-community conflicts that become self-perpetuating cycles of violence (Fratkin, 2004; Pike et al., 2010). They are also among the world's most marginalised and poorest people (Schlee, 2013). But the mental health impacts of pastoralists' exposure to such violence and social inequities are less often the object of study.

2.6. Mental health systems

Globally, mental health systems face critical challenges of scarcity, inequity, inefficiency, a low perception of the need to seek help and related barriers to effective health delivery. These issues seriously affect mental health systems in LMICs (Chisholm et al., 2016; Jacob, 2017;

Jacob & Patel, 2014; Knapp, & Whiteford, 2007; Patel et al., 2008; Peterson, Bhana, Flisher, Swartz, & Richer, 2010; Saraceno, et al., 2007; Saxena, Thornicroft, Shatkin, & Belfer, 2004; Wang et al., 2007).

2.6.1. Mental health resources and service delivery in LMICs

Currently, more than 85% of the world's population live in 153 LMICs. Unlike HICs, LMICs fail to make available sufficient financial resources, and the human and physical infrastructure required for building, maintaining and delivering satisfactory mental health services (Jacob, 2017; Li et al., 2010). But even in HICs where resources may be more available, patients' needs are frequently not met. These include human rights violations, neglect, and experiences of stigma (Dudley et al., 2012; Jacoby et al., 2008; Mehta & Thornicroft, 2014; Newton & Garcia, 2012; Randal et al., 2012; Rosen & McGorry, 2012). Most people with mental illness, even in HICs, fail to access the care they need – the treatment gap – and consequently, huge gaps persist between the burden posed by mental illness and available resources committed to prevent and treat patients (Chisholm et al., 2016; Liu et al., 2017; Read, Adiibokak & Nyame, 2009; Tomlinson et al., 2009; WHO, 2011). Studies show that SSA has the largest treatment gap where an estimated 90% of people with severe mental illness in Ethiopia fail receive care (Fekadu et al., 2019) while in South Africa, up to 92% of those who need mental healthcare do not access such care (Audet, Ngobeni, Graves & Wagner, 2017; Docrat & Lund (2019).

Until 2015, mental health was largely the missing partner in global health initiatives. For instance, it was not part of the Millennium Development Goals (MDGs) (Dudley et al., 2012; Skeen, Lund et al., 2018; Lund, Kleintjes, Fisher, & The MHAPP Research Programme Consortium, 2010; United Nations Millennium Project, 2005; WHO, 2015).⁵

In LMICs, the lack of resources and failure to prioritise mental health in public health has crippled the health systems' capacity to offer adequate mental care. This reflects in poor service organisation, inadequate human resources for mental health and absence of public health leadership (Chisholm et al., 2016; Saraceno et al., 2007). Thus, there is urgent need to

⁵ In 2015, the WHO committed to promoting mental health and well-being as one of the targets of Sustainable Development Goal 3. However, it remains to be seen if national governments can commit to this initiative by investing appropriately in mental health.

scale-up evidence-based mental health interventions through building up mental health services at all levels of existing health systems (Saraceno et al., 2007).

For Jacob (2017), besides low priority funding, there exist human resource gaps and poor infrastructure, lack of mental policy and legislation to direct mental health programmes and services. These issues frustrate the development of sustainable mental health systems, especially in LMICs. For instance, one third of all countries globally have neither a mental health policy nor programme. Moreover, nearly half of LMICs lack functional policy frameworks. This slows down service delivery and contributes to the burden of preventable suffering and disabilities among affected people (Callard et al., 2012).

A significant burden of mental illness suffered globally is strongly linked to CAMH difficulties that persist into adulthood and old age. These difficulties include mental, neurological and substance abuse disorders that occur in childhood and adolescence (WHO, 2019). In SSA, however, there are few data on understandings of childhood mental health issues, particularly intellectual disability (Kpobi & Swartz, 2018; McKenzie, McConkey, & Adnams, 2013; Njenga, 2009). This is mainly due to the lack of adequate capacity to distinguish intellectual disability from other forms of childhood disability. There is as such a gap on how intellectual disability in children is conceptualised in many parts of SSA (McKenzie et al., 2013). More importantly, it is consistently demonstrated in the literature that the scarcity of mental health services is aggravated by the governments' failure to pay sufficient attention to CAMH (Akol, Moland, Babirye, & Engebretsen, 2018; Kleintjes, Lund, & Flisher, 2010; McKenzie, et al., 2013). An evaluation of patterns of mental health services in four SSA countries, namely Ghana, Uganda, South Africa and Zambia highlights a deficiency of relevant policies, legislation, programmes, and human resources and services (Kleintjes et al., 2010). It further shows that stigma and the low priority given to mental health are equally critical factors holding back sufficient investments in CAMH (Kleintjes et al., 2010).

2.6.1.1. Management of mental illness in Uganda: a historical overview

In Uganda, limited historical evidence exists about the management of mental illness. In the 1950s, mental healthcare was integrated in a well-built and largely functional national health system. By early 1970s, Uganda's healthcare system was considered to be one of the best in

Africa (Dodge & Wiebe, 1985; cf. Pringle, 2019). It was well designed and integrated; services were provided at smaller units in villages while regional hospitals served towns and offered referral services. Resources and staffing at all levels were sufficient, with an efficient public health system (Dodge & Wiebe, 1985).

However, the economic decline and political turmoil that Uganda faced between the 1970s and the 1980s left the entire network of social service in virtual collapse. The health system also collapsed and service delivery deteriorated (Dodge & Wiebe, 1985; Dodge, 1986; cf. Pringle, 2019). Mental healthcare suffered significant deterioration followed by long-term neglect. Mental healthcare only regained importance on the public health agenda in 1996, when the government established a mental health programme under the Ministry of Health to coordinate mental health services in the country. After five decades, Butabika hospital⁶ was re-developed, including the revamping of six regional units with a 34-bed capacity each (Ministry of Health [MoH], 1999, 2000).

Later reforms saw the formulation of the National Health Policy (NHP) and the Health Sector Strategic Plan (HSSP).⁷ Both instruments provided basic frameworks for integrating mental health into Primary Healthcare (PHC) (MoH, 1999, 2000). A recent assessment of mental health policy, legislation and integration of services into the public health system however, infers that despite the reforms, service delivery mechanisms face critical challenges. The mental health policy remains a draft despite having been developed in 2000. There is also no mental health plan⁸ that can effectively inform service reform in Uganda (Kigozi, Ssebunnya, Kizza, Cooper, & Ndyabangi, 2010).

2.6.2. Health-seeking behaviours and pathways to care

People's healthcare utilisation, which includes health-seeking behaviours and decisions to choose particular pathways to care, is rooted in social life. In this regard, both illness beliefs and a complex range of social processes shape such behaviours and decisions (Jones, 1994; Kirmayer & Swartz, 2014). The processes involve different sectors and actors within the healthcare systems that include bio-medical practitioners, indigenous healers, family and

⁶ Uganda's national referral mental health hospital.

⁷ The instruments have since been revised and upgraded into the National Health Policy 2010 and the Health Sector Strategic Plan II, 2005/06–2009/10 respectively.

⁸ A draft policy that was prepared in 2000 is yet to be approved and become operational.

friends (Kleinman, 1980). These actors address different social, cultural, psychological and biological needs of patients and their caregivers. Consequently, they affect how people view mental illness, make (or delay to) contact with health systems and treat their conditions.

Several studies have investigated health-seeking and pathways to care for mental illness in both HICs and LMICs (Abbo, 2011; Akol, Moland, Babirye, & Engebretsen, 2018; Forbes, Crome, Sunderland, & Wuthrich, 2017; Kilbourne et al., 2018; Kohrt et al., 2018; Schnyder, Panczak, Groth, & Schultze-Lutter, 2017; Nuri et al., 2018; van der Watt, Das-Brailsford, Mbanga, & Seedat, 2019). Findings consistently reveal that several factors influence health-seeking for mental illness. These factors include the low perceived need to seek care, illness beliefs, financial constraints, limited infrastructure, and diverse pathways to care. In addition to these factors, poor facilities, shortage of trained mental health providers, and stigma are also said to inhibit health-seeking by affected populations. Pathways to care means the courses/routes that people choose which lead them to health resources required to manage the illness (Anderson, Fuhrer, & Malla, 2010; Kirmayer & Swartz, 2014; Nuri et al., 2018). But the nature of pathways to care is complex and involves a range of contacts that can add to delay in treatment (Kleinman, 1980; Nuri et al., 2018; van der Watt et al., 2019).

A global systematic review of the determinants and nature of the pathways to care of sufferers with a first psychotic episode shows that health-seeking may evolve into a pattern of responses (Anderson et al., 2010) that are intended to initiate contact, access resources for mental health and ultimately utilise available care and therapies for mental illness. The targeted therapies for mental illness include the services of bio-medical practitioners, traditional healers and local resources such as home remedies. These services collectively form a complex web of community resources for mental health (Anderson et al, 2010).

A number of studies from SSA also indicate that people use different community resources for mental health, which include the services of traditional healers (Abbo, 2011; Abbo, Okello, Ekblad, Waako, & Musisi, 2008; Adjei et al., 2013; Akol et al., 2018; Kpobi & Swartz, 2019; Musisi, Okello, & Abbo, 2010; Patel, 1998; Sorsdahl, Flisher, Wilson, & Stein, 2010; Swartz, 1996; van der Watt et al., 2019). These studies have shown that many people tend to prefer the services of traditional healers to psychiatric care because they are thought to offer holistic and culturally sensitive care. On the contrary, it has been argued that some

traditional healing practices may be unsafe and harmful to mental patients (Abbo, 2011; Sorsdahl et al., 2010; Swartz, 1996). In a study in South Africa, Sorsdahl and colleagues found that traditional healers mixed herbal preparations with other substances such as methylated spirits to treat mental illness. Such treatment, the authors argue, could potentially be harmful to patients (Sorsdahl et al., 2010). In the same vein, a review of transcultural psychiatry literature in South Africa (Swartz, 1996) indicates that, despite the many calls for the recognition of the mental health role of indigenous healers, their healing practices have been associated with the increase in witchcraft-related murders and abuse in the country. Similarly, a study of profiles and outcomes of traditional healing practices for severe mental illnesses in Uganda (Abbo, 2011), indicates that ritual murders, particularly child sacrifice have been attributed to unethical dangerous behaviours of some traditional healers. Nevertheless, people continue to seek help from traditional healers due to a lack of alternative forms of care, including bio-medical services (Abbo, 2011; Akol et al., 2018; Becker & Kleinman, 2013; Brolan et al., 2014; Kpobi & Swartz, 2019; Swartz, 1996).

Moreover, where the services of both bio-medical practitioners and traditional healers exist, they may present competing resource demands. These put extra restraints on the users' choice of pathways to care (Anderson et al., 2010; Lund & Swartz, 1998; Kleinman, 1980). The users' ability to choose between pathways is also significantly influenced by contextual factors. These include socio-economic, political, psychological and religious factors (Helman, 1994; Rubel & Hass, 1996). The delay in initiating contact with care constitutes a major source of unmet need for mental healthcare, even for people who finally seek help. It is vital that structural and individual factors that inhibit access and use of mental health services must be addressed (Becker & Kleinman, 2013; Kirmayer & Swartz, 2014).

2.7. Culture and mental illness in SSA

The question of the relation of culture to mental health has been central to the development of theory and research in cross-cultural psychiatry for the last four decades (Good, 1977; Good, 1997; Kirmayer, 1984, 2007, 2018; Kirmayer & Swartz, 2014; Kleinman, 1977; Kleinman, 1980, 1988; Swartz, 1998). Culture provides the local idioms of distress: the language which specific cultural groups use to express the experience and mediation of distress in their life worlds (Nichter, 2010). Culture is therefore a source of concepts that should be carefully examined in order to interpret the meanings that particular social groups and institutions

attach to mental illness (Kirmayer, 2018; Kirmayer & Swartz, 2014). There is, though, limited literature about cultural understandings of mental illness in most of SSA. The review that I present below, therefore, focuses on earlier aspects of local ethnopsychiatry, the lay explanatory models (EMs) of mental illness (1970s to 1990s), case studies of EMs of mental illness conducted in the recent past, and local concepts of mental illness in conflict-affected settings of Africa.

2.7.1. Local ethnopsychiatry

In relation to interpretations of aspects of local ethnopsychiatry in SSA, Ndeti and Mburu (2006) describe some useful insights about culture and mental illness. Citing Prince's (1960, 1964) and Asuni's (1972) studies among the Yoruba of Nigeria, and those of Carothers (1953) in Kenya, Ndeti and Mburu (2006) note that cultural theories of the aetiology of mental illness made causal attributions to supernatural powers and ancestor spirits. These forces were known to act through human mediums to punish mental patients or their relatives. Other aetiological theories implicated personal acts of sorcery and witchcraft invoked by one's neighbours, kin and distant clans acting in revenge, punishment or jealousy. Mental health was also linked to natural causes: substance abuse, cerebral malaria, head trauma and other physical illnesses (Ndeti & Mburu, 2006). The illness interpretations and taxonomies among the Yoruba closely matched the Western nosologies of mental illness such as schizophrenia and depression (Prince, 1960, 1964, cited in Ndeti & Mburu, 2006, p. 9).

Despite laying the ground for theorising about culture and mental illness in SSA cultures, scholars such as Carothers held false ethnocentric beliefs about the African mind. Carothers asserted that Africans had greater difficulty in understanding the strangeness of psychotics than Europeans. Moreover, that the "normal African mentality resembled that of European psychopaths" (Oyebode, 2006, p. 323). This reflected essentialist thinking – an ideology that defines people by means of "othering" – marking people who appear different as socially inferior (Said, 1978). This ideology characterised an ignoble imperial legacy that sought to assert psychological domination and control over colonised groups in order to exploit them (Becker & Kleinman, 2014; Kirmayer, 2018; Pringle, 2019). Yet, essentialism persists in cross-cultural psychiatry. For instance, cross-cultural psychiatry continues to misrepresent African medical systems and modes of thought as magical and irrational (Jenkins, 2018; Rasmussen, 2008).

The earlier works, however, were critical to laying the foundations for the study of local ethnopsychiatry. They primarily provided knowledge and understanding on how mental illness was conceptualised in the specific SSA cultures. Understanding local cultural ideas of illness lends us a critical methodological tool for the interpretation of indigenous metaphoric and symbolic meanings of illness. Ultimately, they form explanatory models (EMs) – people’s ideas of illness and treatment. These are important because they explain questions of why, what, and how of the illness (Kleinman, 1980; cf. Weiss & Somma, 2007).

2.7.2. Lay EMs of mental illness (1970s – 1990s)

Patel (1995) reviewed the available literature on mental illness beliefs in diverse SSA cultures published from 1970 to 1994 (Patel, 1995). The review reveals that SSA cultures have a rich diversity of mental health beliefs. However, there are shared concepts within such a diversity of cultural beliefs of mental illness. While most cultures use separate concepts to refer to the mind and body, they share some concepts of mental illness with bio-medical concepts. Psychosis is understood differently as compared to neurosis. It is recognised as madness and classified as illness of the mind. In contrast, neurosis is not perceived as mental illness but as somatic experience. However, cognitive features of mental illness are much less emphasised as compared to behavioural and somatic features. The local concepts of aetiology and classification of mental illness reflect a religious cosmology. There is a strong belief that external social and natural agents cause illness. Given some similarities and, above all, the significant differences in the local and bio-medical concepts of mental illness, Patel (1995) argues that integration of these concepts can expand the knowledge-base of cross-cultural psychiatry and promote global mental health.

An appraisal of innovations in global mental health (Patel, 2014b) echoes the significance of integrating local and bio-medical EMs of mental illness in mental healthcare interventions in low resource settings. It illustrates that global mental health efforts that seek to reduce the treatment gap in these settings have often focused on addressing the supply side barriers to mental healthcare. These barriers include shortage of treatments and lack of specialist human resources. Such an approach is grounded in three key assumptions about the nature of mental healthcare: what comprises a mental healthcare intervention; who a mental health provider is; and what a mental healthcare setting is. More fundamentally, however, the appraisal argues that the focus on addressing the supply side barriers only most often creates a credibility gap.

This refers to a mismatch between health specialists' EMs of mental illness and those held by the local people (Patel, 2014b). The appraisal argues that this mismatch can be greatly reduced by using different innovative models of care, including integrating culturally appropriate EMs in mental healthcare interventions. This strategy of integrating culturally appropriate EMs in mental health interventions help to address the demand side barriers of mental healthcare. In so doing, it expands access to mental healthcare interventions and improves their efficacy, especially in low resource settings (Patel, 2014b).

Recent case studies of lay EMs of mental illness in SSA from the last 15 years provide evidence that is in keeping with the findings of the review of studies of EMs of mental illness in SSA cultures (Patel, 1995) and the evaluation of innovations in global mental health (Patel, 2014b). They also show how knowledge of cultural understandings of mental illness can enhance the effectiveness of interventions for mental health in SSA.

2.7.3. Recent case studies of EMs of mental illness in SSA

In this sub-section, the review draws on literature on recent case studies of EMs of mental illness in three regions of SSA: Southern Africa (Mozambique and South Africa), West Africa (Nigeria and Ghana), and East Africa (Tanzania and Ethiopia).

2.7.3.1. Southern Africa

Patel, Simbine, Soares, Weiss, and Wheeler (2007) conducted an epidemiological assessment of mental health in rural and urban Maputo, Mozambique. The aim was to inform the development of comprehensive mental health policy and planning, and make available reliable data about mental health in Mozambique. The mental disorders targeted were seizure disorders, psychoses and what was referred to as “mental retardation” (intellectual disability). These were found to be more prevalent in rural than urban Maputo, and Mozambicans' awareness of bio-medical EMs of mental disorders was minimal (Patel et al., 2007). Instead, participants held supernatural causal models of mental illness and used traditional medicine for recourse as found elsewhere in Africa (Patel et al., 2007).

To contribute data regarding traditional healers' understanding of mental illness in South Africa, Sorsdahl and colleagues explored the basic concepts of mental illness, including treatment in Mpumalanga, South Africa (Sorsdahl, Flisher, Wilson, & Stein, 2010). The

healers conceptualised mental illness as a distinct category of illness which manifested in severe behavioural disturbances such as violence, picking up garbage, talking randomly, walking for long periods of time and undressing in public (Sorsdahl et al., 2010). Despite the healers' awareness of many causes, they believed that witchcraft and spirit possession were the most frequent causes of mental illness. They used the local term *amafufunyana* to describe severe mental illness caused by witchcraft. Conversely, they recognised mental illness originating from spirit possession as *ukuthwasa* and interpreted it as a calling for one to become a traditional healer. The healers treated mental illness using a mixture of ingredients from both traditional herbal medicines and modern substances. Sordahl et al. (2010) thus argue that a partnership between traditional healers and psychiatrists can improve diagnosis and treatment of mental illness.

2.7.3.2. Western Africa

An evaluation of lay beliefs about causes of mental illness and factors correlating with such beliefs in south-western Nigeria found supernatural factors to be the most reported source of affliction. Other common causes of mental illness were misuse of psychoactive substances and alcohol. Old age and familiarity with mental illness significantly influenced such beliefs (Adewuya & Makanjuola, 2008). The authors argue that the EMs of natural and psychosocial causation of mental illness and treatment contrasted with those of biomedicine as found in Germany and Canada. Further, psychiatric patients could face blame and stigma due to the belief that drug (alcohol) misuse results in self-inflicted illness. Society could also perceive patients as distasteful and dangerous if mental illness were linked to supernatural factors. However, traditional healing may be perceived as more efficacious and preferred to biomedicine. Thus, cross-cultural variations exist in the pathways between causal beliefs and health-seeking between Nigeria and Germany and Canada (Adewuya & Makanjuola, 2008).

Similarly, Ikwuka, Galbraith, and Nyatanga's (2013) study of causal attribution of mental illness among the Ibo in south-eastern Nigeria found that they held supernatural, biological and psychological causal models. Participants' religion and education were significantly correlated with their psychological and biological attributions but no paradigm shift occurred at the causation-model level. Hence, supernatural attribution of schizophrenia was more significant than biological and psychological attributions. The results showed no paradigm shift from superstitious to scientific ideas of causation (Ikwuka et al., 2013).

A study of family carers' beliefs of mental illness and their influence on help seeking of mental illness patients in different cultures in Ghana found that participants held different ideologies of causation (Quinn, 2007). Ghanaians in urban areas believed in bio-medical ideas of mental illness, such as personal breakdown due to work pressure. In rural Ghana spiritual factors such as curses, bad spirits and charms were thought to cause mental illness. The differences between causal models strongly influenced acceptance of patients within Ghana, and help was sought from traditional healers (Quinn, 2007). While variations in education could explain the different ideologies of mental illness, the universalist approach had limited use in explanations of mental illness. Understandings of mental illness were thus culture specific, implying the influence of culture in shaping beliefs of mental illness in Ghana (Quinn, 2007).

2.7.3.3. Eastern Africa

A descriptive survey of women's experiences of distress during pregnancy in Dar es Salaam, Tanzania, elicited local idioms of distress and perceived causes of "problematic pregnancies". The local idioms were intended to inform cultural adaptation of a depression assessment tool (Kaaya et al., 2010). The women used several local idioms to frame their recollections of pregnancy-related psychological distress. These include *kusosoneka* (extreme sadness), *kuwa na mawazo mengi* (thinking too much), *kukosa nguvu* (lack of energy) and *kujisikia kuchoka muda mwingi* (feeling tired most of the time). These idioms of distress match symptoms of depression, as it is known in western psychiatry. Socio-economic, bio-medical and supernatural factors were the most commonly attributed causes of psychological distress during pregnancy. Therefore, the knowledge of the local idioms can inform adaptation of tools for future analysis of depression (Kaaya et al., 2010).

A qualitative study in Butajira, Ethiopia, examined the societal recognition of problematic distress states in the postnatal period and their relation to Western conceptualisations of postnatal distress (Hanlon, Whitley, Wondimagegn, Alem, & Martin, 2009). The study also sought to relate the occurrence of distress states to sociocultural patterning of the postnatal period. Results showed that participants described culturally problematic distress states occurring in the postnatal period, which closely related to the Western construct of postnatal depression. In particular, problematic distress was recognised as manifesting through various behaviours that included sadness, irritability, hopelessness and suicidal ideation (Hanlon et

al., 2009). Yet, participants did not associate these behaviours with any specific illness afflicting the mental health of mothers in the postnatal period. And the expression of these behaviours by postnatal women was attributed primarily to their exposure to psychosocial difficulties, namely poverty, marital discord, exclusion and insufficient care from husband. Consequently, the study argues that the relationship of such distress states to the postnatal mental disorders identified by international diagnostic criteria needs further exploration (Hanlon et al., 2009).

Following a population-based survey that reported the absence of psychosis amongst the Borana pastoralists of southern Ethiopia, a qualitative study investigated how serious mental disorder was understood in this isolated group (Shibre, Teferra, Morgan, & Alem, 2010). It found widespread awareness of severe mental illness among the Borana. The local ideas regarding severe mental illness also closely compared with western conceptions of psychosis. *Marata*, which referred to severe mental illness, was believed to afflict adults, while *sarki* (a syndrome of CMDs) was linked to disturbances of mood, anxiety and substance-related problems. It was also thought to be transitory or self-limiting (Shibre, et al., 2010). *Marata* was diagnosed when an individual demonstrated severe disturbances of behaviour that violated social norms, but attribution of thought disturbances to *marata* was less emphasised. Behavioural disturbances included violence, aggressiveness, restlessness, and roaming, shouting, burning houses and disturbed eating habits (Shibre et al., 2010). Although people with *marata* could improve, they were never cured. They lost the capacity to work, care for self and family, and suffered severe dysfunction. Shibre et al. (2010) conclude that studies of mental illness in isolated communities can benefit from combining quantitative and qualitative methods.

2.7.4. Culture and mental illness in conflict-affected African settings

In a rapid ethnographic assessment, Ventevogel, Jordans, Reis, and Joop de Jong (2013) reported on local concepts of psychosis and non-psychotic illness in four conflict-affected settings of Africa – Kwajena Payan and Yei (South Sudan), Butembo (Democratic Republic of Congo – DRC), and Kibuye (Burundi). The aim was to generate data to assist in integrating mental health activities into existing public health programmes in these countries. Despite variations in the specific defining features of illness by setting, the local concepts of psychosis referred to suffering severe behavioural and cognitive disturbances. Madness was

described as *moul* (Kwajena, South Sudan), *mamali* (Yei, South Sudan), *erisire* (Butembo, DRC), and *ibisazi* in Kibuye, Burundi (Ventevogel et al., 2013). Although, psychosis was attributed to spiritual, natural and psychosocial causes, spiritual attribution was more prominent but varied by setting. Spiritual causes included bad spirits (from rivers, lakes or rocks), disturbed ancestral spirits, violating taboos or being cursed or bewitched. Psychosis was perceived as an abnormality in need of treatment. However, no care was sought except in DRC where biomedicine was available and deemed effective (Ventevogel et al., 2013).

Non-psychotic illness was described as *nger yec* and *yeyeesi* (South Sudan), *amutwe alluhire* (DRC), and *ibonge* (Burundi) (Ventevogel et al., 2013). *Nger yec* (“cramped stomach”), *yeyeesi* (“many thoughts”), *amutwe alluhire* (“tired head”) and *ibonge* (depression-like symptoms) related closely to major depression because they manifested in feeling overwhelmingly sad and social withdrawal. However, they also presented with unique symptoms that suggested suffering anxiety. These include “green diarrhoea” for *nger yec*, “headache” for *yeyeesi*, “confusion” and “irritability” for *alluhire*, and self-remorse and preoccupations for *ibonge*. These illnesses were mostly attributed to psychosocial factors: loss and worry. Bio-medical care was not sought for afflicted persons since they assumed normal functioning upon receiving emotional support from relatives, traditional healers and community members (Ventevogel et al., 2013).

While the local concepts of mental and psychosocial distress in the four settings shared common features with mainstream psychiatric categories, they were not necessarily identical. Thus, they were used as practical devices to enable people to bring order, and attach meaning to chaotic and disturbing experiences as they sought to end their suffering. The concepts were also localised and revealed how contextual factors shaped illness experience.

These studies stress that local concepts show how people’s ideas of mental illness, experience and perceived aetiology determine health-seeking in SSA. The studies also reaffirm the importance of understanding cultural EMs in the care of afflicted people (Adewuya & Makanjuola, 2008; Ikwuka et al., 2013; Kaaya et al., 2010; Patel, 1995, 1998; Patel et al., 2007; Quinn, 2007; Shibre et al., 2010; Sorsdahl et al., 2010; Ventevogel et al., 2013). Clearly, understanding local concepts of mental illness can inform planning of mental health interventions in resource-poor settings, especially areas recovering from conflict (Ventevogel

et al., 2013). Unlike Ventevogel et al.'s (2013) study, the other studies provide useful insights regarding emic views of mental illness from relatively peaceful, orderly and settled contexts of SSA. These are also contexts with relatively secure livelihood systems. Also, unlike the Quinn (2007) and Ventevogel et al. (2013) studies, the other studies are population-based surveys. These do not provide an in-depth perspective of the context, meanings, and interpretation of mental illness by the people (Maxwell, 2012). What is missing are the perceptions of the nomadic pastoralists themselves of mental health. I have thus far reviewed and discussed literature on lay EMs of mental illness from other SSA countries. In the following section of the review, I move on to Uganda where my study takes place.

2.7.5. Uganda

In Uganda, data on lay conceptions of mental illness had begun to appear in tandem with the then evolving national health system. However, there was a shift from a culture of vibrant research to that of total scarcity ensuing from the economic crisis and political turmoil of the 1970s and 1980s. Orley's (1970) ethnography of culture and mental illness among the Ganda is a seminal piece. It sought to clarify lay categories of thought among the Ganda in rural central Uganda in relation to the psychiatric conceptualisation⁹ of mental illness. Orley (1970) specifically examined thoughts on mental illness: its origin, causality, prognosis, treatments and attitudes towards afflicted people. Earlier, Edgerton (1966) conducted a quantitative assessment of local people's attitudes towards and beliefs regarding psychosis among the Sebei and Pokot (Suk) of northwest Kenya, the Kamba of south central Kenya, and the Hehe of southwest Tanganyika. Ethnographic methods were used to elicit local terms for psychosis in order to adapt survey tools to the local context. Edgerton (1966) found social, cultural and psychological correlates of ecological differences between the Sebei and Pokot agro-pastoralists, and the Hehe and Kamba agriculturalists. However, the study lacks ethnographic impetus regarding an in-depth analysis of cultural knowledge of mental illness in the four societies.

⁹ Previously, I have referred to bio-medical/scientific understandings of mental illness as Western conceptualisations. But this is a loose concept that may evoke confusion as it refers neither to a specific culture/tradition nor geographical location. I will henceforth use the concept "psychiatric conceptualisation" as referred to in the DSM-5 (American Psychological Association [APA], 2013) and ICD 10 (WHO, 1992).

2.7.5.1. “Diseases of the brain” and “diseases of the heart”

According to Orley, the Ganda conceptualised mental illness as diseases of the brain, and diseases of the heart. The former were classified into four categories: *eddalú* (violent madness), *ensimbu* (epilepsy), *obusiru* (foolishness) and *kantalooze* (dizziness) (Orley, 1970). Each of these diseases had similar features as those classified in psychiatry. People with *eddalú* (violent madness) were known to throw stones, abuse others, run around naked and refuse to eat food. *Ensimbu* (epilepsy) presented with *grand mal* seizures, causing sudden falls, unconsciousness and jerking of the whole body that lasted for some time. Then, the person urinated, frothed at the mouth, bit the tongue, and slept for about an hour. However, she could hardly recall anything about the fit after regaining consciousness (Orley, 1970).

The Ganda also described mental illness as diseases of the heart because the heart was thought to be the seat of emotions. Two common conditions linked to neurosis troubled the heart: *emmeme etyemuka* (the pounding of the heart with fright) and *emmeme egwa* (a general body weakening and failure to eat). However, the Ganda also recognised other conditions that were relevant to psychiatric analysis: *amakiro* – a postpartum illness that could cause the death of the mother or her baby, and *eyabwe*.¹⁰ This was a convulsive illness in small children in which the body was hot but the feet were cold. Others were *akawango* (persistent headache) and *enjoka* (stomachaches) (Orley, 1970).

2.7.5.2. Concepts of aetiology and attitudes towards people with mental illness

The Ganda also classified mental illness in terms of beliefs of aetiology. The classifications were *eza kyejjira* (illnesses that come by themselves) and *ez'eddogo* (illnesses sent or caused by witchcraft); *ez'amaanyi* (strong) and *ez'ennafu* (weak), and Kiganda and non-Kiganda (Orley, 1970). Kiganda illnesses included *eddalú* (madness) and *ensimbu* (epilepsy). These were said to be traditional since the Ganda knew about them before the advent of Arabs and Europeans. *Ez'amaanyi* (strong) illnesses were thought to be sent by others using *eddogo* (witchcraft) or brought by *balubaale* (spirits or hero-gods). Though traditional therapy was sought, *eddalú* (madness) and *ensimbu* (epilepsy) were known to be severe and did not cure. Biomedicine was not sought, as it was considered not useful.¹¹ *Ez'ennafu* (weak) illnesses

¹⁰ *Amakiro* is seen as a disease of promiscuity; it comes when a pregnant woman commits adultery with many different men, while *eyabwe* is caused by “their” (children’s) bird (*ennyonyi eyabwe*) – an eagle (Orley, 1970).

¹¹ Such illnesses were considered “strong” because they could neither respond to available traditional therapy nor biomedicine. Moreover, the traditional art of healing was thought to have been largely lost over time.

were non-Kiganda illnesses. They included *ez'ekizungu* (“those [common infections] of Europeans”), which were treated with biomedicine (Orley, 1970). The Ganda greatly feared and disliked *eddalu* (madness) and *ensimbu* (epilepsy) because these were bad and chronic illnesses and linked to *eddogo* (witchcraft). Also, afflicted people were seen as violent and dangerous, and thought to have spoilt brains, and thus be foolish. They also brought shame to their relatives. Yet, *ensimbu* (epilepsy) was considered highly infectious. The afflicted were thus stigmatised, treated as invalids, abused and isolated from others (Orley, 1970).

2.7.6. Recent views on local/Ugandan concepts of mental illness

2.7.6.1. The Ganda and Basoga

Research on culture and mental illness was to the best of my knowledge absent in Uganda until the last decade (Abbo et al., 2008; Okello & Musisi, 2006; Teuton, Bentall, & Dowrick, 2007). These in-depth studies among the Ganda and Basoga, a comparable Bantu ethnic group in eastern Uganda, provide new insight into how lay beliefs influence the interpretation of selected categories of mental illness as classified in psychiatry.

Teuton et al. (2007) sought to inform service-delivery models by exploring and comparing indigenous and religious healers' EMs of psychosis among the Ganda in central Uganda. The healers held multiple and complex EMs of psychosis. Psychosis was understood to manifest in culturally inappropriate behaviour and was described using various local concepts. *Eddalu* referred to severe psychosis, while *akazole* and *kalogojo* described its milder forms. To have a “disorganised” head was called *kutabuka mutwe*, and *kizungu* (White man's) “madness” was linked to affliction with infectious diseases like malaria, HIV/AIDS and syphilis.¹²

The healers' EMs of the aetiology linked psychosis to spiritual and physical factors more than to psychological factors. Spiritual causes included angry or neglected ancestral spirits, and malevolent spirits sent by witchcraft. Individuals suffered because of transgressions of social and moral rules (Teuton et al., 2007). However, religious healers regarded psychosis as a manifestation of evil or punishment by evil spirits for one's refusal to engage in indigenous rituals. They also implicated psychological factors, mainly individuals' negative internal reaction to adversity, including failure to manage difficult personal and social problems,

¹² Teuton et al. (2007) explain that, according to the Baganda worldview, Arabs and Europeans are believed to have brought such illnesses to Buganda. Hence, they are outside the remit of indigenous medicine.

namely poverty, HIV/AIDS, and family conflict (Teuton et al., 2007). *Kizungu* “madness” was associated with infectious diseases and considered amenable to psychiatric treatment. Non-allopathic healing services offered by the healers were utilised to treat psychosis brought by spirits. Indigenous healers divined and offered cleansing rituals but the religious healers offered psychological care – counselling and giving social support to affected individuals. Teuton et al. (2007) conclude that Uganda needs a flexible approach to mental illness care; one that integrates non-allopathic and bio-medical models of care.

The Okello and Musisi (2006) and Okello and Neema (2007) studies of Ganda lay EMs of depression articulate new evidence, which augment Orley’s (1970) findings. The Ganda use somatic idioms such as *omutwe omutambuse* (a mixed up head) to name and interpret depression. Depressive experience is linked to strained social relations, especially failing marital relations and inability to provide for family needs. Affected persons use lay sources of care, namely family, close friends, experienced elders and religious leaders who offer support through counselling or talking over the problems. The Ganda recognise recurrent (episodic) depression as psychosis with a symptom formulation reflecting the DSM-IV classification. *Misambwa* (clan gods) or *mizimu* (ancestral spirits) are believed to cause psychosis. Thus, it is labelled *ebyekika* (clan illness) and treated traditionally. However, help is sought from psychiatrists if psychosis causes disruptive behaviour. Body pains symbolise distress, contextualised in everyday social relations and the EMs of depression contrast with psychiatric conceptualisations (Okello & Musisi, 2006; Okello & Neema, 2007).

Abbo et al. (2008) found that the Basoga use different concepts to classify and interpret contrasting experiences of mental illness. So, mental illness is identified as either *eddalu/ilalu* or *kazoole*. *Eddalu/ilalu* refers to schizophrenia while *kazoole* means mania. The Basoga believe that *eddalu* presents with episodes that are more serious and without remission. However, *kazoole* is perceived to be less severe and presents with normality between episodes (Abbo et al., 2008). In terms of aetiology, *eddalu* is cultural, and is as such treated traditionally. *Kazoole* is caused by physical factors, and patients are treated bio-medically or the illness is self-limiting. The results reaffirm Patel’s (1995) observation that lay ideas of mental illness can validate psychiatric tools. Thus combining emic and etic views lends psychiatric tools the cultural sensitivity vital to the study of mental illness (Abbo et al., 2008).

2.7.6.2. The Acholi

Studies with the Acholi of northern Uganda document and describe views consistent with the in-depth studies above (Akello, Richters, & Ovuga, 2010; Betancourt, Speelman, Onyango, & Bolton, 2009; Roberts, Odong, Browne, Oca, Geissler, & Sondorp, 2009). In a rapid ethnographic assessment of local concepts of mental illness among Acholi internally displaced persons (IDPs),¹³ Betancourt et al. (2009) describe the local concepts as relevant to the psychiatric diagnostic terms. IDPs described anxiety or depression-like disorders as *two tam*, *par* and *kumu* and conduct-related problems as *kwo maraco/gin lugero*. *Kwo maraco/gin lugero* relate to the psychiatric disorders of mood, anxiety and conduct. Yet, *kumu* also had specific cultural symptoms such as sitting while holding one's cheek in the hand or a refusal to greet people. The lay concepts thus can be used to validate the psychiatric diagnostic tools among the Acholi (Betancourt et al., 2009).

Roberts and colleagues (2009) explored the social determinants of overall physical and mental health and health-seeking among Acholi IDPs. IDPs' exposure to traumatic events caused "over thinking" and subsequently "madness" and physical ailments. "Over thinking" was attributed to *cen* (the spirit of a deceased [killed by another] person/evil spirit) returning to disturb its killer. This affected physical health and led to an emotional sense of loss of freedom. Physical ill health was also attributed to lack of food and income due to poverty and loss of land. This further caused worry and uncertainty, which resulted in poor mental health. Health-seeking involved use of both biopsychosocial health services and services of traditional and faith healers as well as support by family and friends (Roberts et al., 2009).

Similarly, a study of common health complaints and quests for therapy by war affected Acholi children reports experience of trauma and related local concepts of illness (Akello et al., 2010). Trauma in children manifested in persistent headaches, *cen* (evil spirits) attacks, chronic pains/aches, something painful moving around the body, *cwinya cwer* (sadness), and *can* (psychological pain). The children's quest for health occurred in the context of medical pluralism; use of sleep medicines (Valium and Piriton) and *atika* (Labiata species) plants, including attending healing services. However, child ex-combatants were also advised to seek forgiveness and reconcile with the victims of violence (Akello et al., 2010).

¹³ Military protected camps were introduced to settle the Acholi people (IDPs) during the over-two-decade-long Lord's Resistance Army (LRA) insurgency in northern Uganda. With the return of peace to the region, most IDPs camps have since been closed and communities resettled in their regions of origin.

These studies provide new perspectives of understanding the relationship of culture to mental illness. This has important implications for mental health systems development for the study communities in Uganda. Nevertheless, the IDPs research represents ethnic Luo-speaking people in northern Uganda, while prior studies focus on ethnic Bantu-speaking groups with relatively better access to healthcare in Uganda. However, none of these recent in-depth inquiries fully engage with culture as a sovereign force, which determines the whole range of dynamics of mental health (Kirmayer, 2007). While both the Sebei and Karimojong are agro-pastoralists, the former inhabit a different ecological and geo-political area in Uganda. Their cultural system is also different. Ultimately, there is no record of how mental illness is understood by the Karimojong.

2.8. Pastoralist populations

Although the world has over 200 million pastoralists, they are amongst the least studied people (Little, McPeak, & Barret, 2008). In terms of demographics, a number of pastoralists inhabit South America, East Asia and Europe. In South America, they inhabit Argentina, Bolivia, Chile and Peru. In East Asia, they live in Afghanistan, India, Kazakhstan, Mongolia and Tibet. In Europe, pastoralists live in Turkey (Fratkin & Meir, 2005; Nori, Taylor, & Sensi, 2008). Yet the majority (60%) live in Africa: the Fulani, Tuareg, Bedouin, the Somali, Borana, Nuer, Maasai, Turkana and Karimojong (Peoples & Bailey, 2009; Schlee, 2013). Regardless of where they live, pastoralists survive by raising, caring for, and subsisting on products of domesticated herd animals: cattle, camels, sheep, goats, reindeer, horses, llamas, alpacas and yaks (Fratkin & Meir, 2005). As earlier noted, pastoralists also live in areas characterised by a lot of uncertainty and risk such as in arid and semi-arid environments (Fratkin & Meir, 2005; Peoples & Bailey, 2009; Pike et al., 2010).

Pastoralists adapt to and transform such environments through nomadism – seasonal mobility in search of variable resources such as pasture and water. This makes pastoralists resilient since they are able to cope with many risks that would otherwise threaten livelihood security, and it also allows them to minimise health risks associated with sedentary life (Little et al., 2008). Moreover, nomadism is guided by the pastoralists' awareness of the periodic variability in forage availability, and hence do not wander aimlessly. Livestock convert what would be inedible wild plant resources into edibles, which pastoralists utilise (Peoples & Bailey, 2009). Livestock is also used for transportation and produces diverse goods and

services for trade. The Maasai pastoral lifestyles, for example, are often used as icons in the global advertising industry (Hatfield & Davis, 2006). However, as noted earlier, state policies often undermine pastoral lifestyle and culture. Cultural, political and economic barriers tend to subject them to a lifestyle characterised by incessant disruption and extreme privation. As a result, they often suffer physical ill health but with no access to healthcare as health systems primarily target settled populations (Fratkin, 2014; Green, 2008; Marchi, 2010; Zinsstag et al., 2006). However, there is limited qualitative understanding of health systems among pastoralists, and in particular the Karimojong.

2.8.1. Pastoralist Karamoja

Karamoja has had a long history of insecurity due to armed, violent raids and persistent conflict (Gray, 2010; Närman, 2003; RoU, 2015). Poor state–people relations have developed since colonialism and become recurrent because of active socio-economic and political marginalisation by the state (Barber, 1962; Gray, 2000; Mamdani, 1982; RoU, 2015; Stites & Akabwai, 2010). This has resulted in a variety of negative consequences, both direct and indirect, such as extreme poverty, chronic famine, poor health, poor infrastructure and lack of access to basic social services (Office for the Coordination of Humanitarian Affairs, 2011; RoU, 2015; WHO, 2007a). These factors have forced the Karimojong into displaced states, particularly women and children¹⁴ (Sundal, 2010; WHO, 2007a). In the discussion, I provide an in-depth analysis of the issue of active political marginalisation of the Karimojong by the state, using an archival review.

For over half a millennium, nomadic pastoralism has remained the most rational and viable livelihood in Karamoja. Livestock notably contributes to the people's cultural, political and socio-economic life. Besides meeting their daily survival needs, it is also used to ratify marriage, and confer status and cultural identity as well as to support aspects of religious life. In this context, cattle raiding arose as a cultural institution where people used non-lethal weapons to replenish livestock wealth lost to epidemics and famine, and only some of the livestock was raided from another group. Hence, cattle raids were highly regulated to enable groups under survival threat to eventually recover by mutual reciprocity (Czuba, 2011; Gray, 2000; Spencer, 2004 [1965]).

¹⁴ The Karimojong warriors have firmly resisted the successive government disarmament programmes and for the last 10 years disarmament has failed three consecutive times, resulting in an escalation of armed conflict and loss of life.

From colonial times, however, the state has made inconsistent policies and taken ad-hoc actions against pastoralism. Mostly, it has confiscated land and denied the Karimojong access to grazing lands and water resources. This has radically alienated them from their livelihoods (Jabs, 2007; Rugadya & Kamusiime, 2013). Since 1979, raiding cattle has changed from what was once low intensity raids to large scale armed violence and intractable conflicts. This has been fuelled by the acquisition of automatic firearms amidst loss of livelihoods (Mirzeler & Young, 2000; Mkutu, 2007; O’Keefe, 2010). Raiding is now the source of much violence, injuries, mortality, famine and displacement.

2.8.1.1. Forceful military-led disarmament and health

After five decades of political neglect, Karamoja finally received the state’s renewed attention through forceful military-led disarmament (Knighton, 2003, 2005). It was launched in 2001 but abruptly ended in 2002 because the army was redeployed to fight the LRA rebellion in northern Uganda (RoU, 2007). It was re-launched in 2004 (and was on going during my fieldwork) based on the Karamoja Integrated Disarmament and Development Programme (KIDDP). This was intended to match forceful disarmament with development interventions (Mkutu, 2008). Even so, KIDDP was linked to disarmament actions that instead caused more suffering in Karamoja (Knighton, 2010; Mkutu, 2010). Despite restoring a fragile peace, the use of “cordon and search” strategy during disarmament led to massive human rights violations: unlawful killings, torture, arbitrary detention, rape, theft and destruction of property. Forceful disarmament has since weakened Karimojong families and social structures (Human Rights Watch [HRW], 2007, 2014; Office for the Coordination of Humanitarian Affairs [OCHA], 2011).

Thus, the health of the Karimojong can be described as a near-humanitarian crisis (WHO, 2007a). The Karimojong have the worst access to healthcare in Uganda.¹⁵ Maternal and infant mortality rates are 558 per 100,000 live births and 105 per 1000 live births compared to the national averages of 104 and 43 respectively (Moroto District Local Government [MDLG], 2018; UBOS, 2017, 2019; UNFPA, 2018). Access to safe water is only 30%, yet the national average is 64%, and access to sanitation is below 1% while the national average is 62% (OCHA, 2009; RoU, 2015). They thus suffer a high burden of curable and preventable

¹⁵ The health indicators are even worse than in northern Uganda where over 20 years of rebellion by the Lord’s Resistance Army (LRA) have left huge losses of life and the destruction of social services in the region.

infections that often result in epidemics and high mortality rates. While poor help-seeking aggravates ill health, it is also linked to poor quality and erratic health services (Gray, 2010).

It is within such a context of adversity, social suffering and survival uncertainties that I situate my research to examine local conceptions of mental illness and health-seeking among the Karimojong. Specifically, I seek to find out how adults conceptualise mental illness; find out adults' understanding of mental illness amongst children; describe children's views of mental illness; and relate the findings to social experience and contextual factors.

2.9. Summary

This chapter has presented a review of the literature that informs and shapes the focus of the research. The following are the key highlights of the review: mental illness causes an enormous health burden globally; adverse social and economic experiences such as insecurity, violence, poverty and physical illness are both determinants and consequences of mental illness; the most affected are poor and marginalised populations; the quality of life for people with mental illness, particularly in SSA is aggravated by poor access to treatment; they are also often victims of human rights violations and stigma; and the knowledge of lay people's EMs of mental illness – cultural understandings of mental illness – informs not only the actions that target them, but also public health interventions that aim to improve global mental health. While research suggests that a diversity of EMs of mental illness exist in SSA, to the best of my knowledge nothing is known about pastoralists, who are the focus of this study, in Karamoja, Uganda. Therefore, in this thesis, I examine local conceptions of mental illness and health-seeking among pastoralists in Karamoja, north-eastern Uganda. Such an understanding can inform the design of culturally sensitive and contextually appropriate mental health interventions for the Karimojong and similar populations in Uganda. The next chapter presents the research methodology.

Chapter Three

Methodology

3.1. Introduction

This chapter presents the research methodology; it discusses the theoretical orientation and the basic models of mental illness. It also describes the research design, selection strategy, data collection methods, data management and analysis. Finally, it addresses ethical procedures that were followed in executing the research, presents the coding catalogue for the research participants and discusses reflexivity.

3.2. Theoretical orientation

The study of mental illness presents a number of conceptual challenges. This is evidenced by the many terms used to define and describe the same phenomenon. Terms include mental illness, mental distress, mental disorder, mental health problems, psychopathology, abnormal behaviour and mental health difficulties, amongst others (Hergenhahn, 2009). Partly, this may reflect the dynamic and multifaceted nature of the concept of mental illness (Golightley, 2008). This also highlights the fact that meanings of the concept mental illness evolve and change over time and space (Lefley, 2010; Summerfield, 2008). More critically, it can reflect the variations in culture, which determines how people conceptualise mental illness in different social contexts (Kirmayer, 2018; Kirmayer & Swartz, 2014).

In trying to understand this dynamic, Kleinman (1988) has argued that conceptions of mental illness and its interpretation in respect of illness behaviours are core aspects of culture. Culture refers to socially shared systems of beliefs, values, and practices of how people define and negotiate social relationships in everyday life; it is a meaning-generating system (Kirmayer & Gomez-Carrillo, 2018; Kirmayer & Swartz, 2014). Culture therefore shapes the way people view mental illness, including how they interpret biological processes that may be linked to suffering (Kirmayer & Gomez-Carrillo, 2018; Wiley & Allen, 2009). Equally, although as a system of meaning culture orients humans to one another and their world, it also forms an ideology that disguises human political, economic and health realities in every society (Good, 1994).

Swartz (1998, p. 5) argues, “every question we ask about culture and mental health depends on how we see the world”. However, given that cultures vary significantly, Swartz (1998) further argues that divergent systems of thought exist about what constitutes mental illness. He observes, therefore, that systems of thought comprise theoretical approaches for understanding mental illness in cultural psychology. These include universalism, relativism and critical approaches, amongst others. In common, these approaches inform the tools of analysis which are used to explain and evaluate mental illness and healing practices in specific contexts. But in terms of ideology and practice, each approach stresses different aspects of knowledge (Swartz, 1998). Given this backdrop, this research was informed by a theoretical orientation that draws on three basic models of mental illness: the bio-medical model, interpretive model and critical model. These models provide conceptual and analytical tools that speak to the contested nature of mental illness, but they also, ideologically, inform care and development of services in specific contexts (Gould, 2010; Karban, 2011).

3.2.1. Bio-medical model

The bio-medical model focuses on disease as the cause of mental illness. Its main assumption is that disease is caused by bodily malfunction, especially the brain (Hergenhahn, 2009; Kirmayer & Gomez-Carrillo, 2018). The model identifies specific bodily abnormalities linked to the causation of mental illness, such as injuries, tumours, obstructions, disease and ingestion of toxins. It also asserts that mental illness is directly inherited through abnormal genes and nutritional deficiencies. Such abnormalities amongst other biological predisposing factors make some people more susceptible to suffering certain types of mental illness (Gould, 2010). In essence, the model adopts a restrictive focus and reduces all suffering of mental illness to disease. It also separates the mental from the physical and thus foregrounds dualism (Swartz, 1998).

For methodology, the model relies on universalism. This strategy assumes that mental illness is universal and the purpose of cross-cultural research is to find the evidence for these universals (Swartz, 1998, 2015). Thus, assessment and treatment of mental illness follows the application of uniform criteria to identify and categorise symptoms in order to facilitate the use of identical forms of diagnosis regardless of the cultural context (Bedirhan, 1999; Kleinman, 1988). The assumption is that once mental illness is described in diagnostic categories, it is amenable to appropriate intervention by the psychiatrist (Banner, 2013).

One of the primary challenges of such criteria is that they are based on deductive/etic assumptions. These are assumptions held by the psychiatrist as an outsider to the life world of the patient. Psychiatrists, therefore, use their power and expertise to assess and diagnose mental illness. Doing so, however, only provides partial analysis of illness since little attention is paid to the patient's explanation of the illness (Kirmayer & Gomez-Carrillo, 2018; Kirmayer & Sartorius, 2007; Swartz, 1998). The bio-medical model is also faulted for being essentialist; it integrates notions of illness over which the patient has little control (Adriaens & De Block, 2013). Such conceptual flaws render the model inadequate for cross-cultural understanding of mental illness. This derives from the failure to access and use local knowledge generated by concepts and methods suitable for the psychosocial analysis of mental illness (Kirmayer & Gomez-Carrillo, 2018; Kohrt & Hruschka, 2010).

3.2.2. The interpretive model

The interpretive model examines mental illness and healing as socially generated facts. Such facts constitute categories that are used to define and give meaning to specific aspects of people's lived experiences (De Maio, 2010). The model argues that the causes of mental illness are psychosocial factors such as human experiences of grief, frustration, and fear. There are also problems of living, namely poverty, unemployment, conflict and social exclusion (Lund et al., 2014; Lund et al., 2018). The model would posit that the influence of these factors on mental illness needs to be examined from the sufferer's emic viewpoint so as to establish its explicit meaning (Swartz, 1998; Wiley & Allen, 2009). The issue is that medical practitioners need to pay attention to the sufferer's language, its meaning and context (Good, 2010).

Kleinman (1977) argues that understanding language and its meanings reveals the sufferer's thoughts and beliefs about illness. Meanings show what is at stake for the sufferer and her support group, especially family members. Thus, meanings are critical for depicting the specific explanatory models (EMs) of mental illness (Bhui & Bhugra, 2002; Keikelame & Swartz, 2013; Kleinman & Becker, 2000). Kleinman introduced the notion of EMs in a bid to guide research initiatives in the new cross-cultural psychiatry. He specifically implored researchers to scrutinise the differences rather than similarities in cultural understandings of mental illness across different societies (cf. Becker & Kleinman, 2014; Kleinman, 1980). Kleinman conceptualised EMs as the ideas, beliefs and values that people hold about illness

and their actions to deal with pain and suffering. EMs, therefore, reveal the multiple realities of illness experience: ideas about aetiology, time and onset of symptoms, nature of illness, course of sickness (including degree of severity and type of sick role) and treatment. At both personal and societal levels, people formulate EMs in response to what they perceive as more distressing or disruptive problems (Helman, 1994; Kleinman, 1980; Weiss & Somma, 2007). Although initially intended for clinical work, the formulation has become an influential research tool in cross-cultural psychiatry (Weiss & Somma, 2007). In this thesis, I draw on Kleinman's EMs formulation to examine lay conceptions of mental illness in Karamoja.

The methodology that informs the interpretive model is cultural relativism. As applied in cross-cultural psychiatry, cultural relativism seeks to understand the meanings of mental illness in subjective terms. Meanings are products of social construction, which are interpreted by individuals within the context of their culture and society (Good, 1977; Kirmayer & Sartorius, 2007; Swartz, 1998). In common, these authors analyse the cultural context of mental illness and show how cultural relativist research makes explicit the meaning of suffering from the sufferer's emic viewpoint; it focuses on the lived experience of illness and distress. As such, it constitutes a shift from the bio-medical notion of disease and its restrictive focus on pathological causes to a more holistic view – to understand the social construction of the reality of mental illness (Karban, 2011; Swartz, 1998). However, although emic views provide convincing accounts of illness, they are not exhaustive. Therefore, we also need the etic to reveal meanings of things in expert ways that lay people may miss, including the influence of social context on illness behaviour (Green & Thorogood, 2004).

3.2.3. The critical model

This model explains mental illness as an outcome of the interactions between various forces within the broader social context (De Maio, 2010; Swartz, 1998). Mental illness as social experience derives its broader meaning from people's life worlds. These include demographic, biological, cultural, socio-economic, political and historical interactions of people's unequal relations of power in society. EMs of mental illness are products of such interactions (Good, 1994; Helman, 1994, 2007; Kleinman, 1980). As with the interpretive model, the critical model embraces cultural relativism and foregrounds it as its methodological thrust. It also adopts a social constructionist stance in the analysis of mental illness (Swartz, 1998). Equally, the model politicises mental illness by challenging the claims

of bio-medical knowledge and practices, which reproduce and perpetuate social inequalities in society (De Maio, 2010; Kleinman, 1988). It is therefore important that practitioners in the realm of mental health deal proactively with inequalities in society. There is a particular need to address social factors such as unemployment, poor housing, poverty, stigma and social isolation that result in the suffering of mental illness (Kleinman, 2009; Lund et al., 2014; Lund et al., 2018).

3.2.4. The mixed interpretive and critical model

Given the complex interaction of alternative factors that underpin the explanation of mental illness as suggested in the literature, I adopted a mixed interpretive and critical model – a critical-interpretive approach (Lock & Scheper-Hughes, 1996) – to research mental illness in Karamoja. This model draws on social constructionist methodology, which argues that the knowledge of mental illness and its experience are socially produced (Good, 1997; Swartz, 1998). It is assumed that the social context and culture determine how disease and illness are identified and categorised and the ways in which meanings are attached to them. Social context and culture also provide the basis of power that is used to legitimise illness experiences in society (De Maio, 2010; Kirmayer, 2007; Wiley & Allen, 2009). As Good (1997) notes, experiences of mental illness are psychosocial and cultural phenomena. They are shaped by the local moral worlds of power and meaning, and constituted as distinctive cultural psychologies. Thus, research must systematically engage the cultural and social processes that impact the suffering of mental illness. In this sense, the critical arm of the research is in conversation with, and complements, the interpretive one in a unified manner (Swartz, 1998).

3.3. Research design

In my research, I used a critical ethnographic research design. This enables the ethnographer to engage in cultural critique by examining larger political, social and economic issues that focus on oppression, conflict, struggle, power and praxis (Davies, 1999; Lock & Scheper-Hughes, 1996). The primary aim is to draw attention to dominant and oppressive social structures as sources of suffering and injustice in society (Cook, 2005; Madison, 2012). This expands the aims and usefulness of interpretive (conventional) ethnography. The latter seeks to describe culture and understand the meanings, context and multiple realities of everyday life from people's emic perspective (Hardon et al., 2001; Robben & Sluka, 2012).

While interpretive ethnographic studies of health allow the ethnographer to engage the social world and meanings of her¹⁶ participants, they tend to limit focus to the analysis of individual or group pathology (Cook, 2005). Therefore, they do not sufficiently examine issues of power, experience and social relations in the analyses of health and illness within broader social contexts (Cook, 2005). In contrast, critical ethnography – reflexive ethnography – focuses on understanding the impact of society’s cultural forms and social structures on human health (Cook, 2005; Davies, 1999). Because of the increased recognition of health and illness as socio-economic and political realities influenced by the dynamics of power and dominance, critical ethnography offers a suitable methodology for health research (Harrowing, Mill, Spiers, Kulig, & Kipp, 2010). Specifically, it offers a more in-depth and reflexive methodology for researching mental health among poor and marginalised people (Cook, 2005). Further, unlike conventional ethnography that speaks for participants by describing “what is”, critical ethnography speaks on their behalf by stating “why this is and what can be done about it” (Cook, 2005, p. 132). Therefore, it studies culture in order to challenge and change dominant economic and political forces that shape local health conditions (Good, 1994).

From this perspective, I sought to understand the Karimojong values, cultural idioms, conceptual categories, indigenous practices, experiences and meanings in the context of their local world. The contexts included participants’ everyday life settings of homes, kraals and related spaces in their community (LeVine, 2010). I would thus have the opportunity to immerse myself in the participants’ local world. Immersion in everyday life activities focuses on fostering interactions with the participants over an extended period. This may involve sharing a drink or food with them when offered (LeVine, 2010). Thus, it enhances the ethnographer’s knowledge of the context in which participants experience their lives and her ability to evaluate their psychological patterns and orientations (LeVine, 2010).

3.3.1. Selection strategy

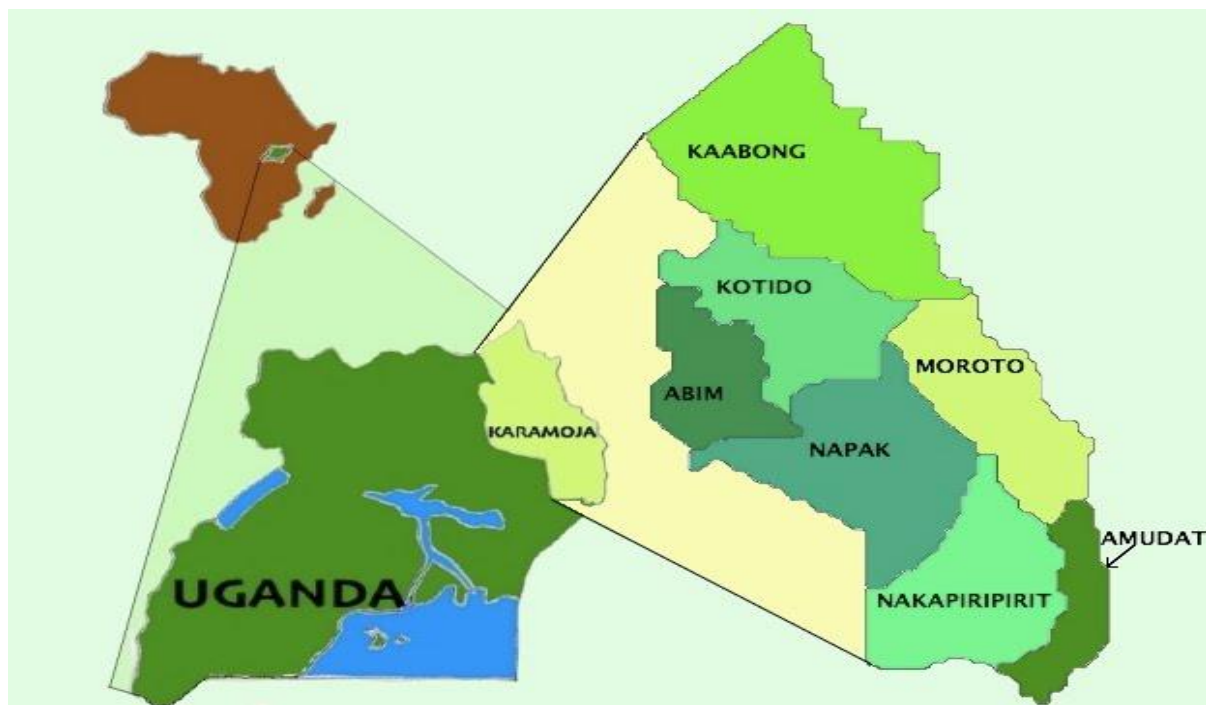
In doing critical ethnography, the process of sampling involves selection of research sites/settings and participants for in-depth study (Green & Thorogood, 2004). This relies on the use of a purposive selection strategy in order to target individuals who fit the criteria of “information-rich cases for in-depth study” (Platton, 1990, cited in Green & Thorogood,

¹⁶ Pronouns representing the female gender are used for purposes of consistency in presentation and discussion.

2004, p. 102). These are desirable as participants to generate a wide range of views that enhance an in-depth understanding (Green & Thorogood, 2004). Such criteria come from one's knowledge of the topic and how the theorising on the ground develops during the research (Henning, Van Rensburg, & Smit, 2009).

3.3.1.1. Study sites

I purposively selected Karamoja as my general study site. It is inhabited by Karimojong pastoralists with a long history of persistent violent armed conflict linked to intra- and inter-tribal cattle raiding vis-à-vis ineffective state control (Barber, 1962; RoU, 2009). Below is a map of the Republic of Uganda showing the location of Karamoja.¹⁷



Map 1. Location of the Karamoja region in Uganda

In Karamoja, I purposively selected two district level sites: Kaabong and Moroto.¹⁸ I was guided by three specific criteria in the selection of district sites: geo-politics, insecurity

¹⁷ Source: <http://projectmoroto.com/wp-content/uploads/Karamoja-Map-3.jpg>, last accessed 21 February 2019

¹⁸ Karamoja region comprises of seven districts: Abim, Amudat, Kaabong, Kotido, Moroto, Napak and Nakapiripit.

Tapac, and Northern and Southern divisions²⁰ in urban Moroto. Moroto town serves as both the district headquarters and the regional administrative and business centre of Karamoja region. The health status of the population is poor, characterised by unduly high infant and maternal mortality. The infant mortality rate (IMR) is reported at 105/1000, while the maternal mortality rate (MMR) is 558/100,000 (MDLG, 2018). These are significantly higher than the national averages of 43/1000 (IMR) and 148/100,000 (MMR) respectively (UBOS, 2019). Malaria is the lead cause of morbidity and mortality, among other preventable diseases that account for the disease burden in the population (MDLG, 2010; MDLG, 2018).

Kaabong district is located in northern Karamoja, with the total population projected at 167,879 people (Uganda Bureau of Statistics [UBOS], 2017). The total land area is 7,300km². Of this, 1,442 km² is occupied by Kidepo valley, Uganda's largest national game park. Moreover, national forest reserves occupy 2,324 km². Kaabong has no natural water source (KDLG, 2010; RoU, 2015). The district comprises nine administrative units. These include eight rural sub-counties: Karenga, Kapedo, Kathile, Kalapata, Lolelia, Loyoro and Sidok, and Kaabong town council. Besides a heavy burden of preventable diseases and poor access to health services, population health is made worse by widespread cattle raid-related insecurity and lawlessness (KDLG, 2010).

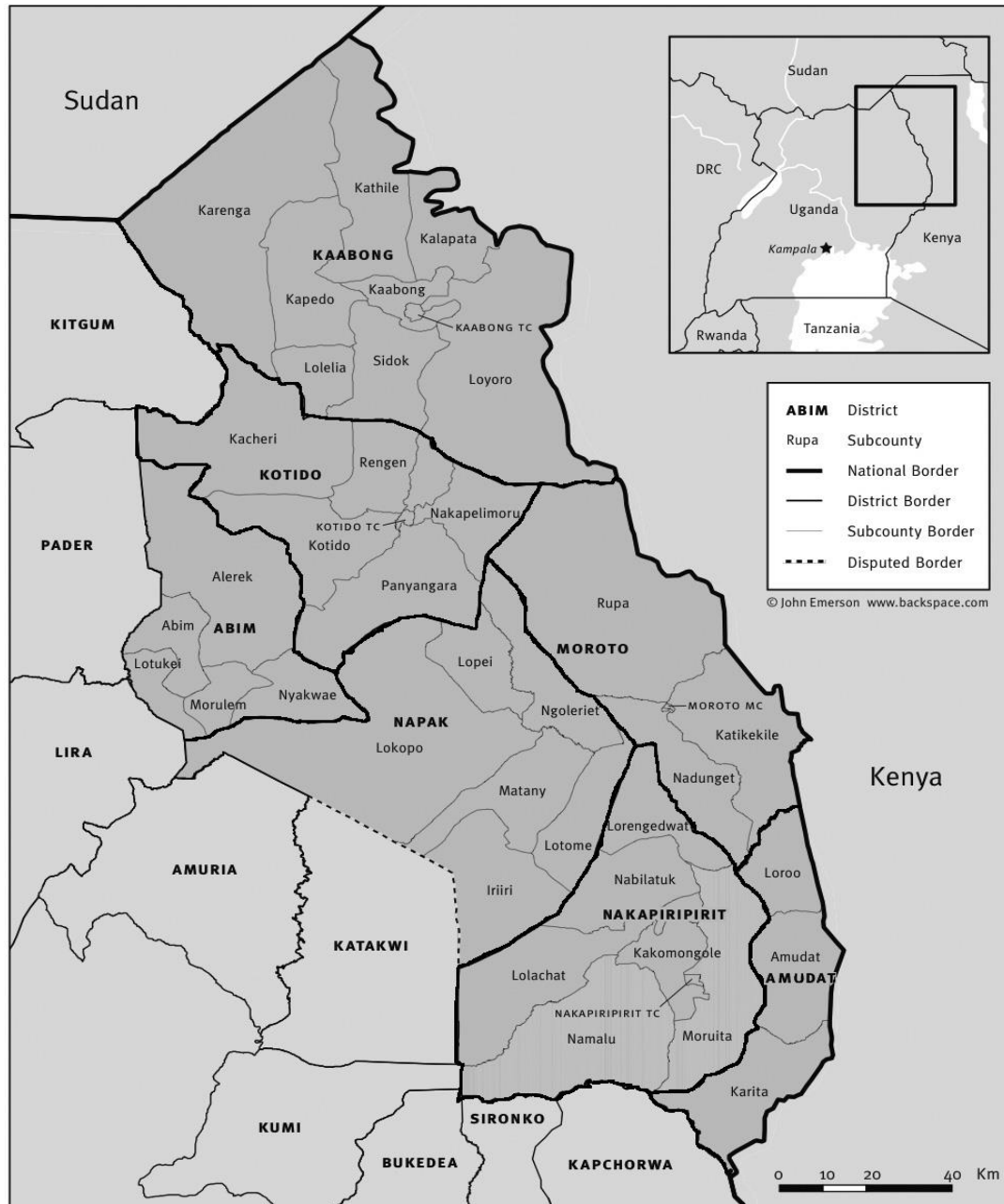
In the absence of a database, infant mortality is estimated at 130/1000 and maternal mortality at 558/100,000 (UBOS, 2017). The main threat to development is insecurity, and is exacerbated by the belligerent relationship between the armed warriors and the state. The warriors frequently engage in running battles with the military (KDLG, 2010; RoU, 2015).

At the district level, two sub-counties of Nadunget (Moroto) and Loyoro (Kaabong) were also purposively selected. This was followed by a purposive selection of two rural village communities for in-depth study: Nadunget (Nadugent sub-county) and Lokonayon (Loyoro sub-county). I selected these villages for in-depth study based on the view that despite the presence of multiple contextual stressors, their impacts on people's lives are varied and at different levels in Karamoja (Dancouse, Akol, & Gray, 2010). In terms of the geo-politics, the villages are located near Uganda's vast and penetrable border with Kenya to the east. Communities here suffer persistent insecurity due to ineffective border control by the state.

²⁰ Within the local government administrative set up in Uganda, urban governance is managed under divisions, which are the equivalents of sub-counties in the rural countryside.

Loyoro sub-county, for example, straddles the warriors' corridor stretching from the border with Kenya to Kotido district to the south west of Kaabong (RoU, 2007). Equally, Nadunget sub-county is always exposed to violent cattle raiding by the Turkana from Kenya (Mkutu, 2008).

People in these areas experience severe levels of insecurity linked to episodes of cattle raiding from the Pokot and the Turkana of Kenya (KDLG, 2010; MDLG, 2010; cf. RoU, 2015). Another related issue is the conflictual relations between the Matheniko and the Dodoth – the two communities that populate Nadunget and Loyoro respectively. These communities raid and counter-raid the other and shift blame one to the other (KDLG, 2010; MDLG, 2010). They also frequently face food security concerns that reach humanitarian emergency levels (OCHA, 2008, 2009). In view of these factors, participants from the above sites were targeted for this research because they shared comparable livelihood threats intensified by ongoing external and internal forces (RoU, 2009; 2015). Below is a map of the Karamoja region, showing the location of the sub-county study sites of Loyoro in Kaabong district and Nadunget in Moroto district respectively.



3.3.1.2. Participants

Final selection was intended to be carried out at the village and community levels, targeting adult and child participants. They were to be purposively selected within the *ngierya* (Manyattas, as the villages of the Karimojong are popularly known), kraals, and markets. The aim of selection from the different sites, such as at household level and in kraals and markets, was to ensure that the research captured as many voices as possible (Green & Thorogood, 2004). However, I made particular efforts to identify and include those participants from households known to be food insecure and receiving food aid. I also intended to pay specific

attention to the selection of participants from those households and families that had recently lost life due to insecurity linked to cattle raiding or had a person believed to have mental illness. In addition, I included specific individuals as participants upon identifying them as practicing traditional healers within the study communities.

In terms of numbers of target participants, the intention was to select as follows: 22 focus group discussions (FGDs), 16 FGDs being for adults (8 for men, 8 for women) and 6 for children (3 for boys, 3 for girls); 10 life history participants; and 30 participants for conversations (20 with adults, 10 with children). Twenty people involved in policymaking and implementation and service delivery in both districts were to be purposively selected and recruited as key informants (KIs). The target categories of KIs were national legislators, government officials working with relevant ministries and district local governments, Non-governmental organisations (NGOs)/development and humanitarian agency staff and local civic leaders. By virtue of their leadership positions and roles in government and development partner institutions, these individuals were deemed knowledgeable about Karamoja and expected to provide information about specific research issues (Green & Thorogood, 2004).

3.4. Data Collection

In critical ethnography, fieldwork is an interactive process between the ethnographer and research participants (Madison, 2012). However, the different forms of human action and interactions such as watching, listening and asking are social practices that require combining and balancing different data collection methods (Green & Thorogood, 2004; Wiley & Allen, 2009). In order to analyse cultural understandings of mental illness in Karamoja, therefore, I sought to use multiple data collection methods infused with mixed strategies and techniques during fieldwork. These included participant observation, life history interviews, conversations (in-depth informal interviews or daily talks), FGDs, in-depth key informant interviews and document review.

Each of the methods used in qualitative research applies a particular theoretical focus on social reality and limits itself to specific lines of inquiry (Berg, 2001). This suggests that the use of a single method in research reveals only certain aspects of reality. This yields partial understanding of the issues being investigated contrary to the ideal of holistic research

associated with ethnography. Ethnographers are as such advised to adopt research strategies that consist of multiple methods in a single research project (Berg, 2001). A multi-method strategy that combines complementary tools and techniques of inquiry enables the ethnographer to cross-fertilise data collection. In effect, she obtains a “better, more substantive picture of reality; a richer, more complete array of symbols and theoretical concepts; and a means of verifying many of these elements” (Berg, 2001, p. 4).

The use of multiple methods facilitates triangulation of data and sources. This strategy helps to offset the flaws in each individual method by capturing multiple perspectives of the research topics (Trotter & Schensul, 1998). There are also benefits to conducting research using triangulation of methods or an integrated methodology. This, for instance, leads to greater understanding of research topics since the use of different techniques helps the researcher to see things and ask new questions about things she would otherwise overlook (Bernard & Ryan, 1998). But triangulation is not just about the use of multiple methods, tools and techniques to gather data on the same phenomena. The process combines the use of multiple researchers, theories, methodologies and data collection techniques in a single investigation in order to increase validity of the data (Denzin, 1978, cited in Berg, 2001, p. 5).

Moreover, ethnographers increase other people’s faith in the validity of their data by triangulating sources of data. Comparisons of meanings from different participants or from the same participant recorded at different times during data collection, for instance, tend to show the truth more than a one-off recording (Green & Thorogood, 2004). Consequently, as a research strategy, triangulation has become a hallmark of doing ethnography. The strategy is not only used to increase the in-depth understanding of issues, but also to enhance validity of the research (Ulin, Robinson, & Tolley, 2005).

3.4.1. Data collectors

The data collectors were a team of four researchers comprising myself (the doctoral candidate/researcher), and three (one male and two female) research assistants. The researcher was responsible for the overall coordination of fieldwork activities: planning, making contact with participants, data collection and data management. The research assistants were graduates of social sciences, bicultural and bilingual speakers with competent skills in social science research and translation.

3.4.1.1. Training

The researcher is not a native of Karamoja and as such lacked adequate skills in *Ngakarimojong*, the local language of the Karimojong. In order to conduct research using an emic perspective, I undertook vital preparatory activities. Before the fieldwork began, I attended training in *Ngakarimojong* for a period of six weeks. I also trained the research assistants regarding the research aim and objectives and orientated them in ethnographic techniques. Further, I, together with the research assistants, conducted a pilot study among the Karimojong living in Kisenyi, a suburb of Kampala. The intention was to refine the research guides through using suitable *Ngakarimojong* terms. During fieldwork, the research assistants participated in conducting FGDs, made translations when needed in conversations, and interpreted contextual issues. Given their competence in the local culture and *Ngakarimojong*, the research assistants were particularly helpful in resolving controversies and intersections between cultural and psychiatric understandings of mental illness. However, I used my basic knowledge of *Ngakarimojong* and fluency in Kiswahili²¹ to seek clarification about issues that arose in the discussions but were unclear to me.

3.4.2. Participant observation

To conduct fieldwork, ethnographers rely in large part on participant observation. This is a strategy that allows the ethnographer to become engaged in the life worlds of participants in order to obtain first-hand accounts of their lived experiences (Murchison, 2010). The ethnographer as a participant observer is able to see things through the eyes of the participants and explain their social context (Green & Thorogood, 2004). The participant observer is the primary “instrument” of research and the credibility of the data collected is based on the authority of “being there” (Green & Thorogood, 2004; Murchison, 2010). The ethnographer nonetheless needs to gain the trust of the participants to act as her teachers and guides in order to be able to understand their viewpoint (Murchison, 2010).

On my arrival in Moroto in July 2010, I was introduced to, and befriended, Alfred. He worked as the youth representative of Nadunget, sub-county to Moroto district. However, part of his duties with the sub-county local government involved community mobilisation activities. He thus knew the area very well. After explaining to him the purpose of my visit, I asked to join him in community mobilisation activities on a voluntary basis and to allow me

²¹ Kiswahili is a Bantu language that is commonly spoken by communities inhabiting the border areas of Uganda, and a second language spoken by most Karimojong.

to live with him, a request he granted. The purpose of acquiring the role of a volunteer in community work was to enable me to make contact and become familiar with the community. In the process, I built trust with, and was able to win the confidence of, in particular, the local gatekeepers. These included civic/local leaders who controlled access to the study community and the people (Green & Thorogood, 2004). For the next three months, I worked as a community volunteer in Nadunget in order to do participant observation.

From February to June 2011, I had another opportunity to work part-time as a medical anthropologist on a violence and barriers to healthcare study in Kaabong district being run by Médecins sans Frontières (MSF) Spain.²² I took up this work opportunity with the aim of widening my research scope. Therefore, I selected and included Loyoro (Kaabong) as my second study site. With the assistance of community-based health workers of MSF, I made necessary contacts with local communities to conduct more observations, especially at the *ere* (Manyatta) level. Through these separate but interrelated engagements, first as a volunteer and then as a medical anthropologist, I was interested in visiting local communities in their *ngierya*/Manyattas in order to observe participants' daily routines and social activities. I was also interested in holding conversations with the participants and, whenever possible, talking to children as they undertook their everyday chores, such as taking herds to graze in the fields.

Observational data were recorded as field notes (hard notes) and annotated notes (Henning, Van Rensburg, & Smit, 2009). Field notes consist of details of observations about participants' behaviours, actions and expressed emotions. Annotated notes capture the participant observer's field experience and interpretations in the form of personal thoughts and feelings (Henning et al., 2009). The major methodological weakness of participant observation as a data collection technique is that the observer cannot study past events, but only those that occur during her presence in the field. Even then, as an outsider, the observer might not have the cultural perspective and community experience required to explore all aspects of the issues being studied (Ulin et al., 2005). The implication is that the observer only gains partial access to the repertoire of cultural knowledge of the people she studies (Murchison, 2010). Therefore, I sought to concurrently engage in conversations and

²² MSF is a medical humanitarian organisation which operated a site in Kaabong to respond to elevated mortality and morbidity rates and the impact of cattle raiding/forced disarmament dynamics.

interviews in order to understand the participants' thoughts, motivations and sentiments regarding acting in specific ways.

3.4.3. Focus group discussions (FGDs)

FGDs are informal conversations held in a group interactive context where people meet to discuss specific topics of interest to the researcher (Dawson, Manderson, & Tallo, 1993; Ulin et al., 2005). Usually, participants in FGDs are individuals who may share a similar context. This may involve living on one village or being members of social networks within a community (Dawson et al., 1993). Social contexts such as the village or social network provide natural groups of people who know each other well. Thus they can easily be brought together to discuss issues that affect them. The main feature of FGDs is group interaction (Ulin et al., 2005). Membership in natural groups helps to maximise interaction and to access shared group culture (Green & Thorogood, 2004). The sum total of group interactions and dynamics stimulate sharing of ideas and debate while participants reflect on the experience of others in the group (Ulin et al., 2005). FGDs also allow researchers space to study non-verbal behaviour and to probe meanings. FGDs further enable participants and researchers to engage in mutual construction of knowledge (Rose, 2007). FGDs, therefore, elicit knowledge that is more detailed and enhances better understanding of issues than the combined information obtained from individual interviews and participant observation (Murchison, 2010).

To mitigate some of the weaknesses of participant observation, and in order to validate observational and interview data, I intended to conduct FGDs with adult and child participants (Ulin et al., 2005). I also intended to conduct equal numbers of FGDs with adults in both village sites and, due to security uncertainties, child FGDs would be held only in Nadunget. The inclusion criteria for adult FGD participants were that they be parents and caregivers living with children. Due to the need to minimise domination and possible distortion of interactions during discussions, no target participant was expected to hold leadership responsibilities in the local structures (Green & Thorogood, 2004). Adult FGDs were also to be disaggregated by gender and held separately in venues agreed on by the participants. For instance, the intention was to hold FGDs with men in places near trading centres and for women under the shade of big trees near their *ngierya*/Manyattas. The data generated through FGDs were to assist in the analysis of contextual issues; participants' views on issues of livelihood sustenance, violence and insecurity, health, gender

and familial relations, and to document cultural ideas of mental illness, including behavioural responses to this experience. Within the group discussion context, I sought to use participatory techniques such as social mapping and preference ranking to elicit views and record notes. The use of participatory techniques was to ensure that participants made substantive contribution to the research (Green & Thorogood, 2004).

With regard to the FGDs with children, the intent was to hold them in places where children play, particularly play spaces near the *ngierya*/Manyattas. These places were identified as suitable venues for discussions since they provide spaces in natural settings where children find themselves together in everyday life (Kielmann, Cataldo, & Seeley, 2011). To minimise tensions and allow maximum interactions among child participants, there were no restrictions on size and group gender composition (Christensen, 2004). The purpose of conducting child FGDs was to document children's emic views of mental illness guided by experience-near research (Geertz, 1974), in which their views are used to define what they see, feel, think and understand by mental illness as members of their communities. I was mainly interested in understanding those behaviours that children were able to recognise and identify as strange enough to constitute mental illness within the Karimojong social structures (Swartz, 1998). While FGDs are a flexible means of data collection, the group context may not be suitable for exploring complex personal beliefs that people hold about their own health and well-being. This and related pitfalls of using FGDs in health research can be overcome by holding conversations with individual participants (Dawson et al., 1993; Murchison, 2010).

3.4.4. Conversations

Conversations refer to holding guided, in-depth, but informal daily talks with individual participants. The aim is to understand how each participant constructs her reality in everyday life contexts (Ulin et al., 2005). Daily talks provide avenues for understanding real culture – culture in action because they deal with complex beliefs and practical issues that directly affect individuals in their everyday life. These include sources of livelihood, gender relations (roles and responsibilities), socialisation of children and health beliefs (Murchison, 2010). My aim was to hold daily talks with adults (males and females) within the natural settings such as *ngierya*/Manyattas and kraals, and upon seeking permission from each participant, audio tape the talks. The target adult participants were the heads of households or their spouses and *ngimurok/emuron* (traditional healers/diviners). These were expected to provide

in-depth data on topics that had not been fully explored during group discussions and participant observation. Moreover, their views would enable me to understand the causal explanation of vulnerability to the existing stressors such as violence, famine and poor health.

For the children (boys and girls), daily talks would be held with those who had actively participated in FGDs to find out each individual child's ideas on mental illness. Other issues to talk about would include family life, socialisation and participation in household chores, sources of emotional and psychosocial distress and care for children with mental illness. I planned to vary the settings for talks with children to include *ngierya*/Manyattas, kraals or play spaces near children's homes, and to record the notes. This was meant to achieve comparison and evaluate the reliability of children's views, and to obtain additional contextual data (Christensen, 2004). I also held spontaneous and relatively short talks, lasting about 15 minutes per meeting. My intention was to allow children to reflect and have more space for their representation in research (Christensen & James, 2000; Kirk, 2007).

3.4.5. Life history interviews

Life history refers to a description of how an individual relates her life experience to the wider context in respect to the past, present and future (Brettell, 1998). As a data collection technique, a life history interview is used to collect data by following a participant's narration of her daily activities, life experiences and choices as she reflects on consequences (Brettell, 1998). It is thus a record of a person's life told to, and recorded by, the researcher (Hardon et al., 2001). I sought to conduct life history interviews in 10 households. The aim was to gain a deeper understanding about the lives of particular individuals in respect of ecological dynamics. At the household level, I intended to visit the participants at different times to record their recollections of life via audiotaped and written records in notebooks. In order to understand the causal explanations of raiding, I investigated the lived experience of the life of a warrior and contextual triggers to a violent life style. I also analysed the post-raiding life of the participant to explore the current problems faced and whether, or not, these had links to mental distress, including coping strategies employed.

Therefore, life histories were intended to generate data on how social structures impacted the life of each individual participant (Green & Thorogood, 2004). The technique serves to provide understanding of the relationship of each individual participant to her culture and

society (Bentz & Shapiro, 1988). However, since the focus of a life history interview is mainly on the participant's subjective experience, interviews would be triangulated with observational data in order to enhance their reliability and validity (Brettell, 1998).

3.4.6. In-depth interviews with key informants

I sought to conduct in-depth interviews with various key informants and record data in notebooks. The persons targeted were those who, by virtue of their positions of authority or experience, were knowledgeable about mental health issues in the community (Hardon et al., 2001). These included government officials and staff working with NGOs/international agencies. It is important to include key informants such as policy makers, service providers and change agents from NGOs in research implementation because they provide an understanding regarding background and contextual issues. Also, when they engage in thoughtful reflections, key informants' views give insights about available resources in relation to the needs of the people being studied (Ulin et al., 2005).

3.4.7. Document review

This refers to accessing and studying existing materials for data that add value to understanding the research topics from historical and contextual perspectives. The specific data sources include printed text and, where possible, oral narratives (Henning et al., 2009). In this respect, I did an archival review to analyse documents for content in relation to the research questions. These include government policies and programme reports, print media and official running records about activities of NGOs and other development actors working in Karamoja (Henning et al., 2009). For Berg (2001), not only do documents form entities of data that add historical value necessary for understanding contextual issues, but they are also used to access and interpret official documentation of details about government policies and programmes (see section 8.2 of this thesis for a detailed discussion of archival data). Documents, for example, the print media, are often an alternative source of gaining insights about sensitive issues such as operations of state security agencies. However, archival data and related documentary sources were to be carefully evaluated to capture the social, historical and cultural contexts in which they were produced (Brettell, 1998).

3.4.8. Transcription and translation of interviews

In qualitative interview-based research, particularly anthropological fieldwork – ethnography – there is the need to understand people’s culture and social life, which requires fluency in their local language (Green & Thorogood, 2004; Hannerz, 2012). Language is a medium through which people interpret and express their experience of the world and of others. In this sense, it constitutes the basic means of interpreting and participating in a given people’s culture (Murchison, 2010; Swartz, 2015b). Quite often, however, many ethnographers face the challenge of studying people whose indigenous language they do not speak. This tends to be the case when an ethnographer comes from a different culture from that targeted for her research (Green & Thorogood, 2004). As a result, she is required to find ways of understanding the local language of that culture. In particular, she has to learn the ways in which that culture uses different terms to interpret, classify and represent their experience of the social world (Green & Thorogood, 2004; Murchison, 2010). Learning and understanding the local language of a culture different from that of the ethnographer has been largely possible in traditional ethnography with extended period of fieldwork. But in short-term research – focused ethnography – as so often is the case today when an ethnographer works in a cross-cultural setting, there is a tendency to rely on the use of interpreters/translators in order to research other cultures (Robben & Sluka, 2012; Green & Thorogood, 2004).

Being a cultural outsider and thus a non-native speaker of *Ngakarimjong*, the local language of the Karimjong, I planned to use different but complementary strategies to enable me to do research with them. As earlier stated, before the fieldwork began, I attended training in *Ngakarimjong* for a period of six weeks. Although through this training I acquired basic language skills, I still anticipated having difficulties in understanding and translating the newly learnt local idioms and related metaphoric terms of the Karimjong. As Swartz (2015b) notes, interpretation and translation are quite complex and demanding research tasks that require language competence, especially when working in contexts where one is a cultural outsider. So, in addition to my training in *Ngakarimjong*, I also made arrangements for working with research assistants. As earlier noted, these were both bicultural and bilingual speakers, and graduates of social sciences with competent skills in social research and translation.

Interviewing and tape-recording conversations and discussions with participants were conducted as part of the fieldwork activities in Karamoja. The interviews were conducted by the principal investigator (JW), assisted by GA as interpreter and CO did the tape-recording, respectively. The tape-recordings were transcribed by LN. Then, the *Ngakarimojong* transcriptions were blindly back-translated verbatim into English by SL. Thereafter, we (JW, GA, CO, and LN) held debriefs to assess the accuracy of the transcribed recordings of interviews. Specifically, we checked the transcribed interviews against their original recordings to ensure that the texts had been validly translated for their content and meaning. Lastly, during the analysis and write-up, JW worked closely with SL who provided further interpretations and clarifications whenever need arose.

3.5. Data management and analysis

Qualitative data analysis is an ongoing, emerging and iterative process (Henning et al., 2009). Data analysis is hence not a linear process but a recursive one in which the researcher moves back and forth to make sense of the data and engage with the interpretation of meanings (Berg, 2001; Braun & Clarke, 2006). Data analysis starts in the field in order to capture how meanings evolve as participants make sense of the realities of everyday life contexts. During fieldwork, data already gathered as field notes are edited for clarity and completeness while tape-recorded data are transcribed or word-processed to enable coding to be done (Henning et al., 2009). As part of the fieldwork activities, tape-recorded group discussions and conversations were transcribed verbatim. The texts were then read to make sense of the data and make reflections in order to shape and guide the subsequent phases of data collection. This helped to reveal those issues that needed further clarity, and more questions were asked to address the emerging issues (Green & Thorogood, 2004).

The ethnographer's focus is to uncover behavioural regularities of everyday life such as language and meanings, rituals and social relations in society (Miles & Huberman, 1994, cited in Berg, 2001). She then has to engage in an analytic process that ensures she identifies and explains how participants live in given contexts, understand and explain things and manage everyday life (Miles & Huberman, 1994, cited in Berg, 2001). Similar to data collection, the analytic process in ethnographic research requires the analysis of data from multiple sources such as observations, interviews, group discussions, conversations and documents (Berg, 2001). Qualitative analysis seeks to discover and reflect the complexity of

reality and to represent the underlying structures that make sense of that complexity (Green & Thorogood, 2004). The ethnographer is therefore tasked to tell the stories of her participants from their viewpoint. She also ought to systematically unpack the stories in order to elicit their broader meanings (Green & Thorogood, 2004).

Consequently, the analytic process demands the use of a pragmatic mixture of approaches to analysis – triangulation (Berg, 2001; Ulin et al., 2005). Triangulation of the analytic process maximises rigour of analysis and the ethnographer's imagination. That is, the ability to shift from one perspective to another while making links between them (Green & Thorogood, 2004). The choice of tools and strategies for analysis should thus be guided by the needs of the research in relation to the data collected (Green & Thorogood, 2004). The analytic process adopted in this research therefore followed a four-stage model based on a triangulation of methods for qualitative data analysis. These include descriptive analysis, content analysis, matrix master sheet and thematic networks analysis.

3.5.1. Matrix master sheet

This refers to a logbook that can be used to organise and summarise large quantities of qualitative data into manageable texts in order to facilitate quick analysis (Dawson et al., 1993). This tool was introduced under the WHO special programme for Research and Training in Tropical diseases (TDR) as an initiative intended to develop rapid assessment procedure (RAP) methodology. This involves the use of anthropological methods in health research to quickly find out the cultural and social factors that influence health and illness in society (Dawson et al., 1993). The methods include conversations, guided interviews, participant observation and FGDs. Using FGDs in health research is particularly useful for understanding a wide range of people's ideas and behaviours of illness (Dawson et al., 1993).

Given the iterative nature of ethnographic fieldwork, data analysis is done simultaneously with data collection. The main aim is to focus research on key issues that are important to the participants in order to explore them closely. This also ensures that data are collected in the best possible way in order to answer the research question (Dawson et al., 1993). The authors argue that the logbook is one of the simplest and quickest ways of preparing FGD data for analysis. In this context, they outline steps to be followed in developing the logbook for qualitative data analysis. These include reading transcripts (field notes) to ensure

completeness, coding by marking sections of transcripts to show main issues raised by participants, and checking if the required data in relation to the research questions have been obtained.

The logbook is prepared in the form of a data summary sheet divided up into columns (Dawson et al., 1993). Thematic categories of the main research issues – codes are written in the first column on the left. The FGDs are written in columns on the right, each FGD in one column. The participants' views, organised and summarised around specific research themes and similar responses across FGDs, are recorded. Equally, responses can be recorded as tallies if the research need is to determine regularities in the data. Comparisons of information can also be made across data in order to identify gaps for further investigation. The logbook is thus used to generate insights across a wide range of views regarding local understanding of health issues in communities (Dawson et al., 1993). Consequently, it serves as an ethnographic field tool that is specifically used to organise information so as to build associations about participants' thoughts and actions in the social world (Murchison, 2010).

Drawing on Dawson et al. (1993), a matrix master sheet – a summary sheet – was used to facilitate preliminary rather than in-depth analysis during fieldwork. During the pilot study, four FGDs (two with men and two with women) were conducted and notes recorded in notebooks. The notes were manually edited for completeness and coded for response categories. Using large flip chart paper (3/4 of a square metre), I prepared a matrix master sheet: an ordinary table with columns and rows to capture summary data for FGDs. Verbal categories were used instead of tallies to clearly visualise issues to participants (see Table 1 Extract of Matrix-Master sheet for analysis of FGD data

).

During fieldwork, the matrix was then used as a template for on-the-spot analysis of data in FGD sessions that were conducted on a day-to-day basis. This was achieved through displaying the main points of the discussion and building consensus among participants on the issues raised (Dawson et al., 1993). Besides, on-the-spot analysis of data helped to further focus the research. For instance, observations made by FGD participants were carefully scrutinised in order to develop question guides for in-depth interviews with key informants and conversations with individual participants. More importantly, on-the-spot data analysis

enabled the researcher and participants to share and validate knowledge in the context of FGDs (Prilleltensky, 1999). In sum, the tool provided a useful framework for flexible data collection, on-the-spot daily analysis and giving feedback to participants as fieldwork developed (Dawson et al., 1993).

The tool is sufficient for analysis if FGDs is the only qualitative data collection method used (Dawson, Manderson, & Tallo, 1993; Dawson et al., 1993). Given the complexity of research issues, varied data sources, including FGDs, were used. This raised the need to bring together issues through synthesis of research themes. To facilitate more rigour and in-depth analysis, data from FGDs, conversations and key informant interviews were thus subjected to thematic networks analysis.

Table 1**Extract of Matrix-Master sheet for analysis of FGD data**

Topic	FGD 1	FGD2	FGD 3	FGD 4	FGD 5	Emerging themes
Health problems	<ul style="list-style-type: none"> - <i>ngidekesyo</i> (diseases) - <i>akom</i> (hunger) - <i>edeke lolibakonyen</i> (yellow fever) - <i>elekes</i> (malaria) - <i>akiurut</i> (diarrhoea) - dirty water; share with animals 	<ul style="list-style-type: none"> - insecurity - many people killed - constant raids - rape of women & girls - <i>eron</i> (famine); no food - <i>elekes</i> (malaria) - <i>aola</i> (cough) 	<ul style="list-style-type: none"> - <i>lodim</i> (HIV) - yellow fever - <i>akom</i> (hunger) - drought & insecurity - raiders kill anybody - rape by raiders - raiders steal food - torture by UPDF 	<ul style="list-style-type: none"> - <i>elekes</i> (malaria) - <i>akom</i> (hunger) - enemies loot food - lack of water - raiders killing us - gunshot injuries - people are maimed 	<ul style="list-style-type: none"> - <i>engac</i> (hepatitis) - frequent deaths - torture by soldiers during search for guns - <i>akom</i> (hunger) - sleeping in the bush 	<ul style="list-style-type: none"> - infectious diseases - insecurity – raids - hunger - lack of water - killings - gunshot injuries - torture
Lay conceptions of mental illness	<ul style="list-style-type: none"> - <i>edeke ka akuman</i> (illness of spirits) - <i>ngikerep</i> - <i>ngiwaiwai</i> - <i>ngibangibangi</i> - <i>akiyalolong</i> 	<ul style="list-style-type: none"> - <i>ngikerep</i> (madness) - <i>ngicen</i> (bad spirits) - <i>ngimasimasi</i> - <i>akirakara/kipapa</i> - <i>akiyalolong</i> - <i>akibwal</i> 	<ul style="list-style-type: none"> - <i>atapapaa</i> (ancestor spirits) - <i>edeke ka ekuvam</i> - <i>ngikerep</i> - <i>ngiwai wai</i> - <i>ngibangibangi</i> - <i>akibwal</i> 	<ul style="list-style-type: none"> - <i>ngikerep</i> - <i>amunorot</i> (possessed by ancestral spirits) - <i>ngimathimathi</i> - <i>ngibangibangi</i> - <i>akiyalolong</i> - <i>akibwal</i> 	<ul style="list-style-type: none"> - <i>ngikerep</i> - <i>ngilam</i> (curses) - <i>ngibangibangi</i> - <i>akirakara</i> 	<ul style="list-style-type: none"> - <i>edeke ka akuman</i> - <i>ngikerep/ngicen</i> - <i>akiyalolong</i> - <i>ngiwai wai</i> - <i>ngimasimas</i> - <i>ngibangibangi</i> - <i>akirakara</i> - <i>akibwal</i>
Mental illness & persons afflicted	<ul style="list-style-type: none"> - <i>ngikerep</i> (adults) - <i>ngiwai wai</i> (adults) - <i>ngibangibangi</i> (children) - <i>akiyalolong</i> (adults) 	<ul style="list-style-type: none"> - <i>ngikerep</i> (adults) - <i>ngimasimas</i> (adults) - <i>akirakara/kipapa</i> (children) - <i>akiyalolong</i> (adults) - <i>akibwal</i> (adults & children) 	<ul style="list-style-type: none"> - <i>ngikerep</i>(adults) - <i>ngiwai wai</i> (adults) 	<ul style="list-style-type: none"> - <i>ngikerep</i> (adults) - <i>ngimathimathi</i> (adults) - <i>ngibangibangi</i> (children) - <i>akiyalolong</i> (adults) - <i>akibwal</i> (adults & children) 	<ul style="list-style-type: none"> - <i>ngikerep</i> (adults) - <i>ngibangibangi</i> (children) - <i>akirakara</i> (children) 	<ul style="list-style-type: none"> - <i>ngikerep</i> (adults) - <i>ngiwai wai</i> (adults) - <i>ngimasimasi</i> (adults) - <i>akirakara</i> (children) - <i>ngibangibangi</i> (children) - <i>akiyalolong</i> (adults) - <i>akibwal</i> (adults & children)

Cause(s)	<p>Ngikerep</p> <ul style="list-style-type: none"> - from <i>akuj</i> (God) - <i>atapapaa</i> (ancestral spirits) need to be appeased - <i>amunorot</i> to be <i>emuron</i> (healer); lineage of <i>ngimurok</i> - <i>ngilam</i> (curses) - <i>akapil</i> (witchcraft) <p>Ngiwai wai</p> <ul style="list-style-type: none"> - blood (genetic) - <i>ngilam</i> (curses) - <i>akapil</i> (witchcraft) - arrest & torture - torture & rape - frustration <p>Ngibangibangi</p> <ul style="list-style-type: none"> - child born like that; no spirit to live - in blood (familial) - <i>ngilam</i> (curse) in family <p>Akiyalolong</p> <ul style="list-style-type: none"> - cattle raided - grief - hunger - deprivation 	<p>Ngikerep</p> <ul style="list-style-type: none"> - we are creations of <i>akuj</i> - <i>akuj</i>'s decision <p>Ngimasimasi</p> <ul style="list-style-type: none"> - <i>ngilam</i> (curses) - <i>akisub l'thuam</i> (bewitchment); they have problems with others <p>Akirakara/kipapa</p> <ul style="list-style-type: none"> - <i>ngicen</i> (bad spirits) attack on pregnant woman & passed to child - pregnant woman suffers <i>akapil</i> (witchcraft) <p>Akiyalolong</p> <ul style="list-style-type: none"> - loss of cattle - death of loved one - frustration <p>Akibwal</p> <ul style="list-style-type: none"> - insecurity - lawlessness - torture - rape - killings 	<p>Ngikerep</p> <ul style="list-style-type: none"> - <i>ngilam</i> (curses) for lack of trust <p>Ngiwai wai</p> <ul style="list-style-type: none"> - <i>ngilam</i> (curses) are familial - <i>akapil</i> (witchcraft) - persistent <i>elekes</i> (malaria) - hard thoughts due to <i>akom</i> (hunger) - <i>etaba</i> (doing snuff) <p>Akibwal</p> <ul style="list-style-type: none"> - relentless insecurity - <i>egurigur alotoma</i> (too much violence) - violent arrests - torture and detention - rape of women - seeing movement of war machines 	<p>Ngikerep</p> <ul style="list-style-type: none"> - <i>ngilam</i> (curses) for breaking taboos (incest, adultery) <p>Ngimasimasi</p> <ul style="list-style-type: none"> - <i>ngilam</i> (curses) for shameful acts - <i>ataapapa</i> (ancestral spirits) for polluting <i>kathite</i> (clan shrine) <p>Ngibangibangi</p> <ul style="list-style-type: none"> - children victims of <i>ngilam</i> (curses) / <i>akapil</i> (witchcraft) - mother attacked by <i>ngicen</i> (bad spirits) - parents violated taboos <p>Akiyalolong</p> <ul style="list-style-type: none"> - death of kin - hunger - frustration - social rejection <p>Akibwal</p> <ul style="list-style-type: none"> - torture and rape - violent arrests - detention - heavy gun fire - killings 	<p>Ngikerep</p> <ul style="list-style-type: none"> - <i>akuj</i> knows - complicated to understand <p>Ngibangibangi</p> <ul style="list-style-type: none"> - difficult birth - illness runs in family - teenage marriage <p>Akirakara</p> <ul style="list-style-type: none"> - runs in some families - vengeful spirit of someone who died of <i>akinakara</i> - <i>ngilam</i> (curses) placed on pregnant women - failure to perform cultural rituals - breaking taboos - <i>akibem</i> (bewitch with evil eye) - <i>ekinyit</i> (a bird of bad omen) 	<ul style="list-style-type: none"> - supernatural factors - social & cultural factors - biological factors - psychological factors
----------	--	--	--	---	---	--

3.5.2. Thematic networks analysis

This qualitative technique is used to explain patterns through highlighting critical connections between the different research themes (Attride-Stirling, 2001). Thematic networks illustrate the critical intersections between research topics and deepen the understanding of research issues by identifying, analysing and reporting themes (Attride-Stirling, 2001). The technique is similar to grounded theory. But the philosophy that informs thematic networks is a flexible framework built on three methodological aspects: realist, constructionist and contextual analysis (Braun & Clarke, 2006). The realist aspect refers to the reporting of experiences, meanings and the social reality of participants. The constructionist aspect examines how events, realities, meanings and experiences shape knowledge in society. Moreover, contextual analysis examines how the broader social context affects reality (Braun & Clarke, 2006).

I used Attride-Stirling's (2001) model of thematic networks. This shows the analytic process as a web-like network or thematic map. This is designed to facilitate better organisation, representation and clear illustrations for systematic interpretation of texts. The model is also a dynamic analytic strategy for answering questions about significant issues that affect the everyday life of specific groups of people (Bradley et al., 2007). Attride-Stirling (2001) demonstrates how designing thematic networks follows a three-stage process. This includes summarising text, exploration of the text and integration of the exploration. At each stage, there are specific analytic steps to be executed. The specific steps carried out in the first (build up) stage of the analysis are: coding, identification of themes and construction of networks. The second stage of the analysis (exploration of the text) is made up of two specific steps: describing and exploring the networks, and summarising the thematic networks. The third stage of the analysis – integration of exploration – involves: interpretation of the themes (Attride-Stirling, 2001). Both stages two and three of the analytic process constitute the interpretive phase of the analysis (Attride-Stirling, 2001).

I began the analysis with the build up stage of the analysis. Data were manually coded. Coding refers to a system of marking and organising field notes in order to easily search and identify connections in data sets (Murchison, 2010). I then read and re-read field notes and transcripts in order to develop an intimate knowledge of the data. This was necessary in order to become acquainted with the salient ideas and issues in the data (Pope, Ziebland, & Mays, 2000). Next, I developed labels that I used to mark lines of texts in order to group and

compare similar texts. In the process, several themes (patterns of meanings) recurring across the texts were identified. Then the themes were used to capture key ideas about the texts in relation to the research objectives and questions (Ulin et al., 2005).

However, to enhance analytic clarity, related ideas are integrated by means of organising themes or thematic structures. These refer to meaningful summaries of ideas that form repeated and broader patterns of important relationships in relation to the research questions (Attride-Stirling, 2001). The different groups of basic themes were then developed into organising themes. Related organising themes were integrated using overarching ideas in the entire text or grand themes. Thus, I developed and mapped out thematic networks to produce coherent and internally consistent accounts of my participants (see Appendices 7, 8 & 9).

3.5.3. Content analysis

Content analysis refers to a method used to systematically read and interpret written documents for meanings, and to establish trends and patterns in texts (Berg, 2001; Krippendorff, 2004; Smith, 2000). The documents may include formal communications, descriptive forms of symbols and visual images – stored artifacts of social communication (Berg, 2001). The rationale for using content analysis derives from the need to understand issues in materials recorded about reality that cannot be directly observed, such as historical events (Krippendorff, 2004). Content analysis enables researchers to reduce large amounts of texts into small and manageable forms of representation. Thus, texts are summarised into content related categories and general trends and patterns identified through coding (Smith, 2000). Codes represent common themes and trends while patterns show relations among themes. Finally, themes are used to describe salient issues in the texts (Krippendorff, 2004).

Field notes from observation data and secondary data obtained through the review of archival documents were manually coded. The general trends and patterns across all texts were identified and context analysed for the relevant themes (Henning et al., 2009). The documents targeted were those that had a specific bearing on the understanding of contextual issues in line with mental illness care and overall health promotion in Karamoja. Such knowledge revealed the general trends, conditions and opportunities for improved mental health outcomes in Karamoja (Berg, 2001). The specific issues highlighted were the development

and implementation of policies and programmes, as well as possibilities of establishing outreach programmes for community mental healthcare.

3.5.4. Descriptive analysis

This refers to an analytic process of reproducing an in-depth picture of an experience, social context or life history as a participant reports it (Green & Thorogood, 2004). Specifically, for life histories, participants' accounts are not subject to rigorous sorting or condensed through coding. Data are edited with minimal coding so that the essence of participants' accounts is captured and interpreted for meanings and actions (Berg, 2001). Since the life history interview is intended to represent subjective experiences, descriptive analysis allows the participants' voice to present individual perspectives of how they interpret their life world (Green & Thorogood, 2004). In order to complement observations, descriptive analysis of life histories was done concurrently with content analysis and participants' accounts are described in their near original form (Green & Thorogood, 2004). Figure 2, below, presents a descriptive model that summarises the processes of fieldwork and data collection.

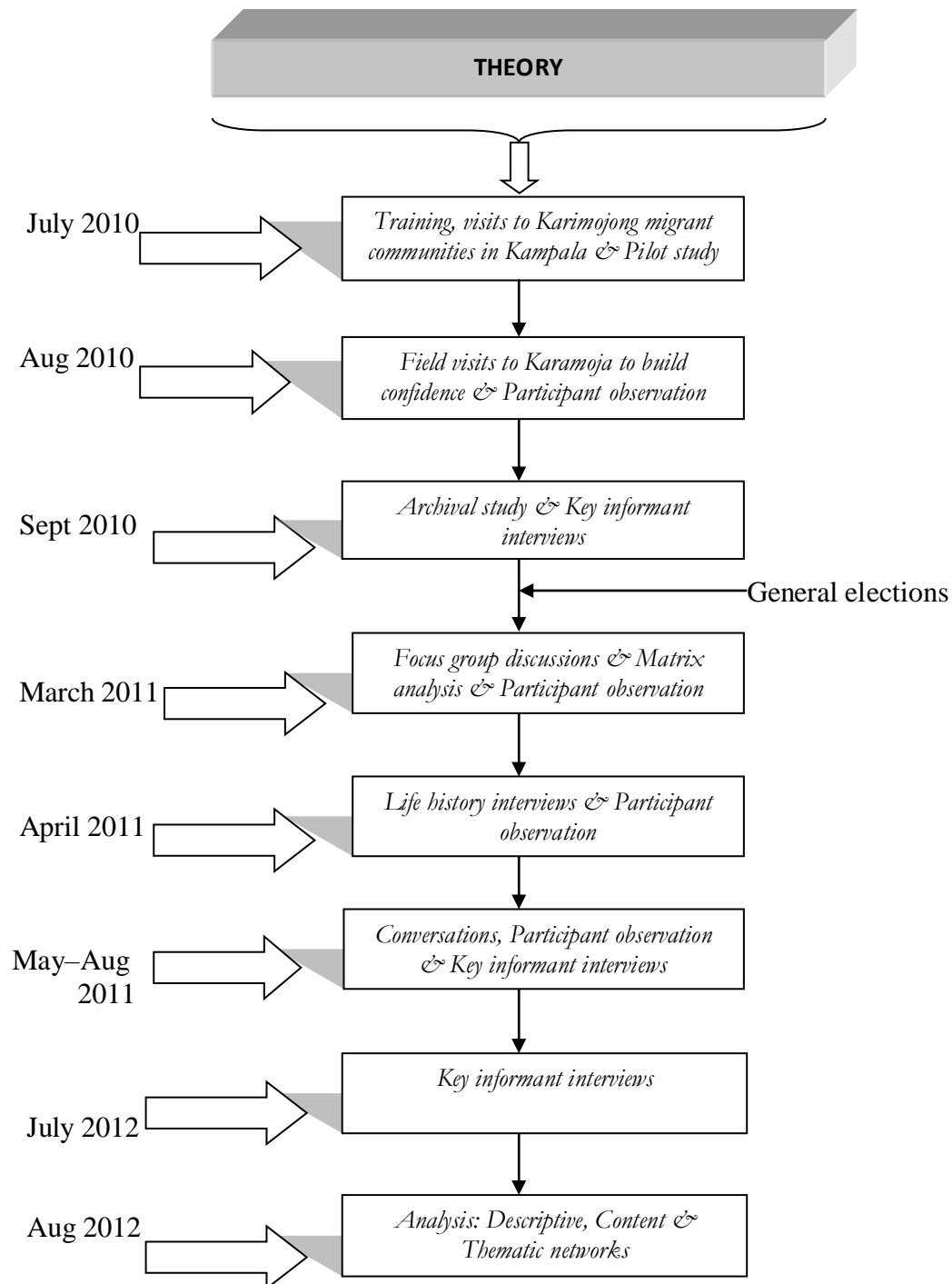


Figure 2. Descriptive model of fieldwork and data collection processes

3.6. Coding catalogue

In order to keep the identities of participants (and key informants) anonymous and maintain confidentiality, I used a specific code to refer to and represent each of the participants. The codes were generated using a coding catalogue that I developed to facilitate capturing of certain important aspects of data collection. These include the technique used to collect data

from each participant/group of participants; participant's gender; and district of origin or site where the participant or group of participants were interviewed (see Table 2).

Table 2
Coding catalogue for the research participants

Data collection technique	Informant code
Life history interviews	LH-M (1, 2, 3, 4, 5) ¹
Conversations	CAM-M (1 – 17) ²
	CTH-M (1 – 3) ³
	CMC-K-2
	CFC-M-4
Focus group discussions	FGA-M-1
	FGC-M-2
Key informant interviews	KI-M-3

Key

¹LH-M-1 = e.g., Life history interview in Moroto with informant number one

²CAM-M-1 = e.g., Conversation with adult male in Moroto, number one

³CTH-M-1 = e.g., Conversation with traditional healer in Moroto, number one

CMC-K-2 = e.g., Conversation with male child in Kaabong, number two

CFC-M-4 = e.g., Conversation with female child in Moroto, number four

FGA-M-1 = e.g., Focus group with adults in Moroto, number one

FGC-M-2 = e.g., Focus group with children in Moroto, number two

KI-M-3 = e.g., Key informant in Moroto, number three

3.7. Reflexivity

This thesis, titled *Mental illness and health-seeking of adults and children: A critical ethnography of Karamoja, north-eastern Uganda* is an initial attempt to study and represent cultural understandings of mental illness among pastoralists. In contemporary ethnography, studying and representing “others” is often a contentious and complex undertaking. This is largely due to ethical and practical complexities involved in interpreting the lifeworlds and meanings of “others”. In highlighting these complexities, Stuart Hall (1977, cited in Madison, 2012) has observed that cultural interpretation and representation have consequences. In

particular, Hall notes that the way in which people are represented reflects how they are treated (Hall, 1977, cited in Madison, 2012). For this reason, ethnographers should account for their influence on the research process. In particular, they must show how their roles in research shape the way knowledge is produced (Green & Thorogood, 2004). As both Robben and Sluka (2012) and Van der Geest (2007) argue, knowledge production is intersubjective experience; it is shaped by interactions between researchers and participants in their quest to interpret the world. And that interaction, so argues Van der Geest (2007), should be based on mutual trust, which allows researchers and participants to share reality. In the methodological literature, this research approach is termed reflexivity, introspection, or doing reflexive ethnography (Green & Thorogood, 2004; Kleinman, 1999; Madison, 2012; Murchison, 2010; Robben & Sluka, 2012).

Looking back on my fieldwork, I can describe the experience as quite difficult, but instructive. When I spoke to people about the idea I was developing for my thesis, they questioned what had inspired me to work in Uganda's most remote region, settled by people who are "backward" and "violent". This view seemed to be supported by the literature where I noted the tendency to construct the Karimojong as people resisting change and integration into national development (cf. Krätli, 2010). But these opinions appeared to run contrary to evidence that the above descriptions are examples of stereotypes which are often used to discriminate and disadvantage marginalised people (Fratkin, 2014; Schlee, 2013). In relation to mental health, there is also ample evidence linking factors such as violence, insecurity, and poverty to suffering mental illness (Desjarlais et al., 1995; Patel & Kleinman, 2003; Wang et al., 2007).

So, inasmuch as I had never been to Karamoja and lacked firsthand experience of the people, I found these constructions quite problematic. They seemed to portray images of a timeless people; those who did not develop at all (Said, 1978; cf. Wijngaarden, 2018). Despite having a background in medical anthropology, the prospect of studying people ostensibly described as "violent" still made me feel anxious. I also struggled to focus the research given the many issues the Karimojong confronted in everyday life. Ultimately, I decided to study mental illness, given its importance in Uganda and in settings of humanitarian crisis such as Karamoja.

When I first visited Karamoja in July 2010, I struggled to locate the headquarters of Nadunget sub-county. In the course of my wanderings I met an elderly man who I asked for help. “Where are you coming from if you do not know where you are going?” he asked. While he did help me to find the office, it occurred to me that I was a complete stranger to him, and I also expected to be perceived the same way by the rest of the Karimojong community. Notably, his question alerted me to the need to seriously think about the strategies to use to negotiate an “insider” status for myself. The other specific concerns related to how best to gain access to participants; how to secure their willingness to participate in the research; and how to ensure my own safety while in the field.

Research has shown that when researchers recognise how their own subjectivity – who they are – influences participants’ thoughts, actions, and interactions, and manage it, they can grasp the latter’s view. This in turn may lead to valid interpretation and representation of their reality (Madison, 2012; Murchison, 2010). However, to have a deep understanding of another’s view requires a framework such as that which critical ethnography offers. In this context, Soyini Madison (2012) outlines three prerequisites for doing critical ethnography: positionality, dialogue with the “other”, and understanding the theory-method nexus (Madison, 2012). Following Madison, I used the tools of positionality and dialogue with the “other” to do research with the Karimojong. Positionality refers to the researcher’s locus or position in the research process. Thus, it describes the researcher’s identities, roles, values, and experiences in relation to people whom she studies (Madison, 2012; cf. Brady, Fryberg, & Shoda, 2018). In clarifying the role of positionality in qualitative work, Madison (2012) states that it enables researchers to recognise their own power, privilege, and biases just as they denounce the power structures that surround their informants.

Being an “outsider”, I was quite aware of the need to negotiate an “insider” status, as noted earlier. I therefore had to think of innovative ways that would help me to achieve an “insider” status. I positioned myself in two ways: as a community volunteer in Nadunget and as a medical anthropologist in Loyoro. In performing these interrelated roles, I realised that I was perceived by the gatekeepers – those who controlled access to information – as a community-based health worker. Particularly, I realised that in the eyes of the gatekeepers (local political and religious leaders, Manyatta heads, elders, and parents), I was regarded as somebody contributing to the well-being of the Karimojong through medical and humanitarian work.

This helped to minimise problems as I quite easily gained entry to the field and made contact with participants, particularly adults. It became apparent to me that I had significantly managed to minimise social distance with adult participants because I succeeded in doing both participant observation and conducting interviews with them. Moreover, they allowed me not only to freely enter their homesteads (Manyattas) but also their houses. Access to such spaces, as I later learnt, was not easily granted to non-residents. As my host and guide, Alfred would tell me:

...you are so lucky to easily work with my people to such an extent of being allowed to enter inside their houses. We rarely allow strangers in our Manyattas. The conditions we live in force us to take security seriously. But I have seen people seem to like and trust what you are doing.

This experience taught me that it is possible for a researcher to establish relationships based on mutual trust with participants if she appropriately assumes meaningful social roles which allow her to contextualise her own positionality (Madison, 2012).

For the children, unlike adults, I observed that even after I had been granted consent and positioned myself as an “insider”, I still had limited access and could not conduct meaningful research with them. To some children, I remained an “outsider”. I was an adult, an elite and “medical” worker, besides being educated. Indeed, I also sensed an inner awareness that I could not easily distance myself from the reality that I am adult, an elite, and educated. Studies on children’s participation in research report that children often face the difficulty of interacting with adults, due to unequal power relations (Christensen, 2004; Kirk, 2007). In order to deal with such potential threats, I offered to help them with chores such as fetching water, and shepherding goats and sheep. This enabled me to build trust and friendship with children, leading to better interactions with them.

Nevertheless, I only managed to collect limited data from them, mainly through participant observation. It was not until they agreed to participate in discussions and conversations that I managed to make real contact with them and collected meaningful data. Through this, I learnt that researchers can only make real contact with participants, especially children, when they have dialogue with them (Crotty, 1998; Madison, 2012). As Michael Crotty (1998) notes, it is only through dialogue that researchers can be able to recognise and understand participants’

perceptions, feelings, and attitudes, and as a result interpret their meanings and intentions. That implies that dialogue with participants allows researchers to draw close to what was most at stake for them (Christensen, 2004; Murchison, 2010). Equally, for Soyini Madison (2012), an ethnographer can only be able to effectively grasp the viewpoint of the “other” when she reinforces her subjectivity – positionality – with participants’ subjectivities through dialogue. Dialogue thus grounds the ethnographer’s subjectivity in the participants’ empirical world and provides the intersection between shared multiple realities. She goes on to argue that compared to the ethnographer’s monologue (written text) of observations, which is static, dialogue between subjectivities produces lively and dynamic meanings (Madison, 2012).

In this context, I used dialogue as a research tool to contextualise and interpret participants’ views about mental illness. For the child participants, it provided intersubjective space, which enhanced our relationships. We were able to exchange roles; I became the learner and they were facilitators. Therefore, through dialogue, I managed to hand over some control to the children and to research with them. This became apparent when they actively shared their views about mental illness with me. This was rewarding because I learnt a lot from them.

Apart from the use of dialogue, I contracted malaria on different occasions during fieldwork in Loyoro in rural Kaabong district. However, on each of these occasions, I had to request anti-malarial supplies from Kampala. I could not access them from the government health facility in the area due to incessant stock outs of drugs. In some ways, my illness experiences alerted me to the struggles that the Karimojong went through to deal with their own illness and maintain their health.

Finally, I hope that this thesis offers a valid interpretation and representation of the Karamoja reality. I also hope that it provides novel and more productive ways of studying Karamoja; ways that can enable one to do so without preconceived notions of people who live there (Said, 1978).

3.8. Ethical procedures

This research received ethical approval from the Health Research Ethics Committee of Stellenbosch University (Ref. No: 10/05/180) and the Uganda National Council of Science and Technology (#SS 2389). The Uganda National Council of Science and Technology

(UNCST) is the government agency mandated to approve and coordinate research in Uganda (see Appendix 5). Research clearance by the Office of the President was also received in order for the researcher to access government archives (see Appendix 6).²³ The research was cleared by the respective Resident District Commissioners (RDCs) as well as Chief Administrative Officers (CAOs) of Kaabong and Moroto district local governments. This was done to ensure that the research objectives did not in any way compromise the already fragile security situation in Karamoja. In addition, permission was granted by the local political and civic leaders in Nadunget and Loyoro. I also sought the informed (verbal) consent of both adult and child participants (see Appendices 1 & 2). The adults included the parents and caregivers of children and key informants targeted in their respective capacities. I assured all participants of the confidentiality and anonymity of information given by them. I also ensured that each of the participants, particularly children, exercised their freedom to voluntarily participate in the study and leave if they so wished. I also informed participants that they were free not to answer any questions that made them uncomfortable and that only the research team would have access to the data. Figure 2, above, presents a descriptive model that summarises the processes of fieldwork and data collection.

3.9. Summary

This chapter has presented and discussed the research methodology. The specific issues include a description of the theoretical orientation and models of researching mental illness. The chapter has also described the research design, highlighting the details of the selection strategy used and the data collection methods, strategies and techniques. These include participant observation, life history interviews, FGDs, conversations, in-depth key informant interviews and document review. In addition, the data management and analysis strategies and the ethical procedures followed in the execution of the research are described. Lastly, the chapter has provided the coding catalogue used to represent the participants and a discussion on reflexivity. In the next chapter, I present the results, focusing on descriptions of research participants.

²³ I received approval and clearance for my research from: 1) Human Research Ethics Committee of Stellenbosch University (Ref. No: N10/05/180), 2) Uganda National Council of Science and Technology (#SS 2389), and 3) Office of the President, Republic of Uganda (ADM 154/212/01).

Chapter Four

Results

4.1. Introduction

This chapter presents results in four sub-sections. First, I present a description of the research participants. Next, I describe conceptualisation of mental illness in adults only and health-seeking behaviour. Then, I describe conceptualisation of mental illness in children and health-seeking behaviour. Lastly, I present conceptualisation of mental illness in both adults and children.

4.2. Description of Research Participants

In this sub-section, I present a description of the research participants. I specifically highlight critical issues and challenges that characterise the daily living context of participants. I also describe the different categories of research participants by data source. These include life history participants, participants in conversations, focus group participants and key informants.

4.2.1. Research participants

Adults and children were interviewed over a period of 12 months (see Table 3). A total of five participants (4 adults, 1 child) were interviewed using life history interviews. Sixteen FGDs, 12 groups with adults and four groups with children, were conducted. Of the 28 participants who participated in conversations, 20 were adults and eight were children. Only adults (19) participated in key informant interviews

Table 3**Description of research participants by data source**

Data source	Participants
Participant observation	Not applicable
Documentary	Not applicable
Focus group discussions	160 adults (93 men, 67 women)
	55 children (33 male, 22 female)
Life history interviews	5 (1 child, 4 adults)
Conversations	28 (8 children, 20 adults)
Key informant interviews	19 (All adults)

4.2.1.1. The daily living context of participants

The daily living context of participants presented here is a description of where they lived. Explicitly, attention is drawn to the type of homes of the participants, their living conditions in terms of hygiene and sanitation and sources of food of those living in Lokonayon and Nadugent villages.

4.2.1.1.1. The concept of “big villages”

The concept of “big villages” was used by one of my key informants, a clan head and elder, to refer to human settlements found in large enclosures in rural Karamoja. Given the density of the settlements, the “big villages” resembled camps (see Picture 1 and 2). A “big village” (*ere/Manyatta*) comprised one community living in several huts in an enclosure. Each village had between 100 and 500 people, all of whom belonged to one clan.

Picture 1. An aerial view of “big villages” (ngierya/Manyattas) of Karamoja²⁴



Source: *MSF* Spain (2011).

²⁴ Apart from picture 1A, the rest of the pictures presented in this thesis are from my photo research in Karamoja

Picture 2. A ground view of “big villages” (*ngierya*/Manyattas) of Karamoja



Source: Photo research in Karamoja by the author.

In this context, the elder explained that over time violence and insecurity had driven people away from their ancestral lands and original homesteads and forced them to live together in “big villages” in relatively safe areas:

... we have been displaced from our lands by armed violence and insecurity... cattle raids... forced us to gather together in big villages... a lot of problems... overcrowding and diseases... that is life in Karamoja... (KI-M-19)

Indeed, such “big villages” existed in the different parts of Karamoja. The “big villages”, wherever they were found, tended to share unique features. They were set up in disguised locations. Quite often, the locations were in relatively “hard-to-see” and “strategic” places. These include thorny thickets, valleys surrounded by rocks, and occasionally on top of forested hills and mountain ranges. These were used as natural and physical barriers to

camouflage homesteads from enemy raiders – settlement areas that offered security advantage against attacks by enemy raiders. For example, one elder told me:

Mountain areas and forested hills act as our natural defences... it is easy to hold back attacks by the raiders... (KI-M-15)

Within the *ngierya*/Manyattas, though the homesteads were built close to one another, they were autonomous. Each homestead had *alaar* – a strong barricading enclosure of wood built around it leaving only one small circular entrance (about half a meter high by half a meter wide) to enable people's access to a path; one that joined a network of winding paths that served the entire village. The network presented itself as an intricate maze. Amidst the maze was the clan head's homestead, and next to it a kraal.²⁵ It is from here that the network of paths originated, leading to other homesteads and finally connecting to the outside of the *ere*/Manyatta. By design, the living pattern reflected seniority, with more youthful warriors living next to the *ere*/Manyatta edge which was surrounded by thorny wood.

In a few instances, the *ere*/Manyatta edge was reinforced by a hedge of drought-resistant and poisonous *eligoi* and *ebuluka* (milk shrubs). These added to natural barriers to enemy attacks because their sap corrodes the human skin and causes blindness. The shrubs had medicinal purpose as well. People used the sap to make body tattoos and the juice from the flowers to treat cattle diseases. At night, *ere*/Manyatta entrances were usually kept closed and secure by tight-fitting branches of poisonous and thorny shrubs. People said that the thorny shrub fittings in the entrance were meant to work on the psychology of the enemies:

... it is a way of trying to scare off enemies. . . these shrubs are poisonous and dangerous. . . that at times helps to instil fear and where possible hold back attacks. . . (KI-M-15)

To open, one had to push the branch of the thorny shrub from inside the village. Otherwise, you would be pierced and injured if you forced to open from the outside. In addition, there were other secret security measures. For example, all *ere*/Manyatta entrances were closely watched at all times (see Picture 3). At night, armed warriors slept on guard disguised at various points within the *ere*/Manyatta, and in the wet season when many cattle were kept in the kraals within the *ere*/Manyatta, armed warriors dug-in and slept in trenches around the

²⁵ Usually, only a few milking cows are kept in the village kraal to cater for the food needs of women, children and the elderly. The rest of the herds are kept in distant kraals within grazing fields.

village. Despite this, the participants said that the insecurity of perpetually living under the threat of attack caused them significant stress.

Picture 3. Children keeping watch over their village entrance during the day



Source: Photo research in Karamoja by the author.

4.2.1.2. The type of homes of the participants

The homesteads in which the participants lived are the traditional huts of the Karimojong, built of mud and wattle and with grass thatched roofing. To provide security, the hut's interior has extra safeguards. It is built like a bunker lying roughly two metres deeper than the doorstep level. A strong wall that is about a metre higher than the door level is built from the centre of the hut to join the wall in which the door is fitted (see Picture 4). These are intended to shield inhabitants from gunshots fired into the hut by enemy raiders at night.

However, apart from the danger caused by gunshots, participants were also exposed to risks posed by fires. Fire outbreaks were reported to be common. Every time there was a fire, whole villages were destroyed resulting in loss of lives and homelessness. For instance, the participants said that on many occasions desperate enemy raiders set villages on fire in order to drive the cattle out. Also, subsequent to relentless drought, accidental fires were common occurrences in the villages. On one of my fieldwork visits in Nadugent, 500 people were left homeless after a fire destroyed the village of Nawanatau (see Picture 5). A media report said a whirlwind drove the fire from a hut when a girl was preparing porridge for the lunch meal. Efforts to stop the fire from spreading by breaking down the fortified wooden fences yielded nothing and all household property, including cooking utensils and water containers, were destroyed.²⁶

Picture 4. A buffer wall behind the door inside a hut in an ere/Manyatta



Source: Photo research in Karamoja by the author.

²⁶New Vision, Monday 20 December 2010.

Picture 5. A burnt hut within an *ere*/Manyatta



Source: Photo research in Karamoja by the author.

4.2.1.3. Hygiene and sanitation challenges

Inadequate hygiene and sanitation contributed significantly to the poor living conditions in the *ngierya*/Manyattas. The nature of congestion, lack of cleanliness and lack of furniture, bedding and clothing was an indication of the severe levels of deprivation in the homesteads. The living conditions of many of the families of participants were further made worse given the fact that a single hut was used for multiple purposes. These included food storage and kitchen besides housing a family of as many as six people.

The core public health components, and in particular, hygiene and sanitation, were extremely limited or lacking altogether in the *ngierya*/Manyattas. Many participants' families neither had access to safe water nor engaged in safe disposal of human excreta. The participants said that their efforts to uphold practices that would ensure good hygiene and sanitation were constrained by the lack of means to buy essentials such as soap. For example, one key informant told me that people went as long as a month without bathing. More critically, poor hygiene and sanitation seemed to be direct consequences of structural constraints, especially

poverty and insecurity. As earlier stated, insecurity forced people to build *alaar* – wooden enclosures for protection around their huts. As a result, for safety reasons they had to crawl on the ground in order to access their homes and those of relatives within the village. The experience of crawling, described by one key informant as “humbling”, exposed people to different risks. Despite skilful crawling and sliding through the paths the participants’ ability to keep personal hygiene was compromised through direct contact with dirt, including human excreta (see Picture 6).

Picture 6. Researcher’s own experience of crawling out of an *ere*/Manyatta



Source: Photo research in Karamoja by the author.

Children were often seen defecating in the little open spaces within the yards of *ngierya*/Manyattas. In a few cases, a pit latrine was found built near the entrance but outside of the village. Even then, the pit latrines were poorly sheltered. Their unfinished walls neither ensured privacy nor provided the convenience that especially adults needed to use them during the day. At night, adults could not use the pit latrines due to the fear of enemies waiting in ambush (see Picture 7).

Picture 7

Picture 7. Unfinished pit latrine structure serving members of an *ere*/Manyatta in Lokonayon



Source: Photo research in Karamoja by the author.

4.2.1.4. Sources of food

Four main sources of food were identified: livestock, food aid, *ikwa lounoi* (food for work scheme) and crop farming combined with foraging. Although the participants said that they made their livelihoods by livestock herding, the appropriation of livestock products had become untenable. Over time, the supply of livestock products such as blood, milk and other dairy stuff, and occasionally meat, had declined markedly. The participants outlined major challenges to maintaining sizeable herds in order to ensure a sustainable livelihood as loss of herds to looters and enemy raiders. Others were recurrent livestock epidemics and a failing supply of dairy products due to drought constraints on proper animal husbandry practices. To offset loss of livelihood due to depletion of herds, participants reported that they turned to unusual livelihood strategies such as food aid, food for work, and crop farming and foraging.

Although intended to supplement livestock production, crop farming was reported as the least sustainable. Drought prevented productive crop farming, apart from occasional small harvests of sorghum. Consequently, all the participants interviewed said that the United Nations World Food Programme (WFP) had registered their households for food aid distribution.

However, not all of them were current recipients of food aid distribution. This was because food aid was distributed only in the worst times of scarcity such as after a long and persistent drought. In addition, following a change in policy, WFP aimed to encourage local communities to produce their own food (Office for the Coordination of Humanitarian Affairs, [OCHA], 2011). In this respect, WFP sought to target only the “most vulnerable” individuals, such as malnourished children, the elderly and people with disabilities (PWDs).

In reality, the change in WFP policy on food distribution meant that less and less food was now available and accessible to the people. In this context, adult participants explained that many people had been compelled to take part in the *ikwa lounoi* (food-for-work scheme). This scheme was being piloted in some parts of Karamoja through the World Vision, an international non-governmental organisation. Under the *ikwa lounoi*, local communities are expected to receive food rations only in exchange for their labour for the development of public works. For example, individuals would only receive food rations proportionate to a predetermined number of hours of supervised labour such as opening up community roads and construction of valley dams. However, the scheme was yet to be evaluated and scaled up. Many local communities remained food insecure as a result. For example, most participants interviewed said their families would go without food during the day and usually have only one meal at night.

As a result, adults would drink *kwete* (local sorghum brew) for most of the day largely as a food source. In contrast, most young children, particularly those left in the *ngierya*/Manyattas, ate the dregs or residue of *kwete* for their lunch meal. Apart from the leftover, they also depended on wild fruits and greens gathered for them through foraging by their mothers. Boys had access to milk by virtue of their herding responsibilities. Boys as young as six years spent little time at home because they would have already acquired skills in herding and grazing. Milking cattle and drinking a portion of the milk was their entitlement as they herded and grazed the herds.

4.2.2. Life history participants

The life history interviews were conducted between the months of March and May 2011. Of the five life history interview participants, four (3 males, 1 female) were adults and one, a male child (see Table 4). Life histories aim to illustrate the individual actor’s perspective of

life in relation to the wider social context, and to highlight information that may not be easily accessed by other methods (Green & Thorogood, 2004). The intimate nature of the interviews, their in-depth nature and specific focus on personal memories, makes it important to briefly describe the biographies of each of the five participants that I interviewed using this method. This will not be done for key informants, participants in FGDs and conversations.

Table 4

Life history interview participants

Participant	Place of interview	Number of visits
LH-M-1	<i>ere</i> /Manyatta	2
LH-K-2	<i>ere</i> /Manyatta	3
LH-K-3	<i>ere</i> /Manyatta	2
LH-K-4	<i>ere</i> /Manyatta	2
LH-M-5	<i>ere</i> /Manyatta	3

4.2.2.1. LH-M-1

On March 13, 2011, I was taking an afternoon stroll around the village to acquaint myself with some of the household tasks that children performed in Nadugent when I met LH-M-1. He was an 11-year-old and in grade four at Loputuk primary school. He, like many of his peers, had come to fetch water from a hand pump borehole sunk near a military detachment located a distance of about half a kilometre from the village. Before this, I had seen him in the company of his mother. This was on two occasions when I had visited their *ere*/Manyatta during my brief stint as a community volunteer. During this encounter, I greeted him and he politely said: “*Ejok, edakitar*” (fine, doctor). The participant associated me with medical work. I asked him what made him think so. He said:

... the last time you came to our village you talked about health in a home and how to stop diseases...

This was an important icebreaker. I told him this time I had come to the village to talk to children and not adults and I asked for his permission to talk to him. He gave his consent without any hesitation.

LH-M-1 was dressed in a torn T-shirt and was without underwear. The shirt had faded from its purple colour to dark brown. It was stained with dirt and marks of sweat. He seemed to always have worn it without washing it. He had difficulty lifting an old 20-litre can of water onto his head. He was all wet as water kept splashing on him through the split top rim of the water can. I offered to lift the water can as we walked home. My intention was also to further minimise the social distance between us and gain his trust, meet his mother and see the home.

From the *ere*/Manyatta entrance, he took me to their home, a small hut. It was the fourth in a semi-circular formation of huts on the left side of the *ere*/Manyatta entrance. The wood fence around it was rather weak. It was almost falling apart and as such was in urgent need of repair. The hut was closed and stood in a nearly empty yard save for the bundle of fuel wood that lay next to its door. “*Maata*”, he called out for his mother but there was no response. He then told me:

She is not home. I think she has gone to see her friends.

I inquired about his family and how many people lived at home. He explained that it was only him and his mother now living in the home. He further explained that:

I am the only surviving child of my mother and my late father. I had a younger sister but she died when my father was still living...

I replied that I was so sorry to learn about the death of his sister and father and then explained to him that I had to leave because it was getting late. We agreed to meet the following day at his home after school. However, as we walked out, we met his mother at the entrance. She also quickly recognised me, addressing me as *edakitar*. She said she was sorry to have missed me but explained that she had been to the next village to see a sick friend. I told her, there was no problem; I would see her the next day in the afternoon.

The following day at about three o’clock in the afternoon, I found LH-M-1’s mother waiting for me at the village entrance. She said she had expected me much earlier and now excused herself, as she had to meet someone else in the next village. However, she inquired if there was anything I wanted her to do for me before she left. I explained to her that I had come to talk to “my friend” (LH-M-1) about schooling but needed her consent to do so. She smiled

and replied: “I have no objection.” She welcomed me to her home where we found LH-M-1 waiting. “Here is your visitor; he wants to talk to you about schooling. Talk to him, I have no problem with that.” She told LH-M-1 and then left.

“Yesterday, you talked about your late father, would you tell me more, what happened to him?” I asked “my friend”, LH-M-1. He breathed in heavily and then said:

Ooh, *papa* was killed last month (February). He was shot and killed near the village by the warriors in a late evening raid on our village. He was on his way home from meeting his friends.

LH-M-1 said that some people had heard his father yelling and then they heard *emudu* (the sound of gunfire). However, the soldiers quickly answered with heavy gunfire and the raid was stopped. He explained, with tearful eyes:

It was too terrifying for everyone to come out of the village. I was too shocked to sleep. *Maata* and I stayed awake the whole night.

I told him I was so sorry and after some silence, he said that the next day they went to the scene and found the body lying there in a pool of blood. Later in the day, the body of his late father was buried at the spot where he had died. Again, after pausing for a while, he went on to explain that both he and his mother were now helpless. They had to beg for food and other things they needed. He also told me that since the murder of his father, he had become terribly scared, that every night he dreamt of somebody holding a machete and wanting to kill him. Sometimes he dreamt of a person shooting another with a bow and arrow and then the arrow man would turn and aim at him.

Talking about school, he said he now had difficulties concentrating in class because every time his friends teased him with death, and he kept remembering horrible things:

At school when I become angry, my friends tell me not to fight. They say if I do not behave well, I will die like my father. I then think of bad things and worry all the time.

He also expressed the fear that he would sometimes miss school especially when he was forced to go to sleep hungry. However, on a positive note, he said that his teachers still liked

him because he had been doing well in class. For example, he said that while in grade three, out a class of 60 pupils, he had passed 9th in the class.

He described being worried about two things. Since his mother drinks like his late father used to do, he was worried that she would also be killed. Second, the fear of losing his mother made him worry about his own life. He said that he felt like he was carrying something too heavy on his head and had no hope for a better life.

4.2.2.2. LH-K-2

LH-K-2 was a man in his late forties. He was dressed in *khaki* trousers and a dark reddish short-sleeved shirt. He kept the sleeves of his shirt folded up. He also wore a yellow *apokot* (a thick arm bangle) on his left arm and *amukat* (used car tyre rubber sandals). Though *amukat* are also used in other parts of Uganda, especially in the north and east, people call them “Karamoja roadways” to depict them and their origins as inferior and as such the sandals are meant for very poor people. Nonetheless, in Karamoja, both men and women wear *amukat* to protect their feet from thorns and sharp stones while they work and walk in the thorny shrubs and on rocky ground.

On three separate occasions, I visited LH-K-2’s *ere*/Manyatta to interview him. Our first meeting was on the morning of April 14, 2011. He had heard us talking as I approached his home with my guide who was also a resident of the same village. When we reached the gate to his home, I asked my guide to go in first, a message that signalled my sense of uneasiness to LH-K-2. “*Lopai* (my friend), you are welcome, feel free to come in. There is no problem”, he said while smiling. That is how I noticed his wide gap between his lower canine teeth. Either the four teeth had been removed or he had lost them in an accident.

He lived in a spacious yard that had three huts built facing each other in a triangular formation, and almost located at the centre of the village. He sat on a stool by the left side of the second hut from the small gate to the home. The home was rather quiet with little indication that there were people around. In contrast, the immediate homes were lively as women and children could be heard talking and laughing cheerfully. He told me that since he was aware of my visit and was expecting me, he had chosen to stay alone. The guide said he had other tasks to attend to shortly and left the two of us to meet. My host started by

explaining that he had a big family with many children so he did not want them to disrupt our discussion. Consequently, he said that he had sent them to his other homes. Soon, I learnt during the interview that the particular reason for sending the children away had more to do with the sensitivity of the issues he was talking about than just disruption per se.

LH-K-2 was boastful while speaking about himself and his family. He put on a wide smile before describing himself as an “old warrior”:

I am now 49 years old and the eldest son in my family. Six of us were boys but as I speak to you, I am left alone. As senior warrior, my late father had many wives and children. Aah, like him, I am also a former warrior; I lived the life of a warrior for 18 years. That was since 1989 until 2007 when I retired.

He went on to explain that he was a polygamous man and had a very big family:

I am married to six wives and we have several children.

Citing survival difficulties as the main reason that forced him into raiding, he told me that he started raiding after the death of his father in 1989. He said his father died and left 78 children under his care. LH-K-2 was the eldest son and inheritor to his late father:

I was overwhelmed by the responsibility of feeding such a big family. At first, I was confused of what to do but later decided to become a warrior and make a living through raiding cattle...

He further stated that raiding cattle offered the best way out because it was lucrative and raiders enjoyed an attractive life style:

...warriors had a lot of wealth in cattle and were respected because they had many wives and children. I was enticed by their life style and in the end I decided to become one [a warrior] myself...

In another interview with LH-K-2 held on April 16, 2011, he spoke about his memories as a commander of a large group of warriors. He said that on numerous occasions he led a big group of fellow warriors, numbering as many as 100, on several successful raiding missions into the neighbouring countries. Nonetheless, there was one particular incident he described

as the most rewarding and memorable in his experience as warrior and the commander of raiders. He exclaimed:

Aah! I cannot exactly remember which year it was... but I think that was my best raid so far. I brought home 260 heads of cattle...

But he quickly added:

I can tell you that it was a very bloody raid...

He said that it [raid] left many people dead and many were injured although he took direct personal responsibility for only seven deaths. Thereafter, he looked down, held his head with both palms and after a long pause of silence, he sighed and then told me:

... you know it is difficult to avoid death in a raid. Either you kill or it is you and your people to die. I think I have had to deal with 50 of such cases . . .

Speaking about how he felt emotionally after going through such experiences, he expressed deep regret and feelings of trauma:

I feel like I took away the lives of my own people. Even after I went through cleansing rituals, the shock and pain inside me remains up to this day...

Later, he said that between 2004 and 2007, his group came under attack by the Uganda people's defence forces (UPDF) – the Ugandan military. He explained to me that because there was little option, he and his group decided to rather be killed engaging the military than surrender and be humiliated. He explained that they survived the military pursuit for quite some time and that the military even resorted to using the helicopter gunships, but still failed to subdue him and his men. Instead, he boasted of how he earned the title of “major” because of his fighting skills:

... yes, I am a fighter... a fierce fighter. Alone, I captured and disarmed a UPDF Major. He pleaded for his life... and I let him go free. That is why I am called “Major”. To date, he is my best friend...

He stated that following that incident, the military opted to involve the local leaders to negotiate with him for peace. He was then promised compensation only if he agreed to surrender and disarm. He explained:

...because I respect our elders, I listened to their advice. I also asked my colleagues to stop fighting... and that is how I also left raiding...

Subsequently, he said that in December 2007, he handed in all the guns that he had in his personal possession to the military. The decision to surrender, however, also seems to have been seriously influenced by the government consideration to “compensate him”:

I have since spent four years waiting for compensation but in vain. I do not know why... the whole issue seriously disturbs me. I am unhappy and keep blaming myself. I must drink to keep down my thoughts...

He also said that he was increasingly growing impatient and often resisted the thought of going back into raiding activities. For example, when challenged whether he would manage to execute a raid, he said:

... in my whole life, the best thing I have ever known is how to raid. Give me a gun now and you will see cows here...

4.2.2.3. LH-K-3

On both occasions that I visited his house, this participant wore a tattered dirty brownish *Suka* (Karimojong traditional dress) and old greenish army underwear underneath it. He also put on a rusty dark-green helmet and striped straps of animal hides as if to decorate himself with a garland of sorts. According to LH-K-3, he was in his late fifties and widowed. LH-K-3's home was located next to open ground behind an empty village kraal. He lived alone in a dilapidated hut without a door shutter. Rubbish, used paper boxes and water cans strew his yard suggesting that he did not attend to it. In contrast, the yards of homesteads nearest to his home were neat and had newly built wood fences around them. The respective entrances to these homesteads were also kept closed apart from one small open access. This access led to the home of one of his cousins who lived with his young nephew – a six-year-old boy and grandson to LH-K-3.

The first time I visited LH-K-3's home I found him standing facing his hut. He held a short stick under his left arm, mumbling to himself and making gesticulations with his right hand. He was acting as if conducting a session with an imaginary choir in front of him. As soon as he noticed me at the entrance of his homestead, he turned and addressed me: “*Afande*” (a

Kiswahili expression that is used to address a soldier who is another's military superior). I greeted him while keeping eye contact as he nodded in response. Before long, his nephew, accompanied by two other male residents of the village, joined us. Children from the adjacent homesteads also kept peeping at us through the openings in the barricades of thorny woods.

Thrice, he repeated the word: "... *afande, afande, afande*". However, this time he spoke very loudly as he flung the *Suka* over his shoulder and complained: "*Akoro, akoro...*" (Hunger... hunger) while touching his belly. Quickly, he opened his underwear and urinated in the full view of everyone in the compound. The children who were watching laughed at his action but that seemed not to bother him at all. Afterwards, he turned to me and said in a rather low tone:

Lopai [My friend], I am hungry, give me 100 Uganda shillings [0.04 United States dollars] to buy food... okay, give me anything. I will pay back when I receive my pension next week from Kampala...

However, before I could say anything, he hastily told me that he felt scared to go to Kampala to receive his pension. He said he feared to cross the Owen falls dam at Jinja. Jinja is a major town located near the source of the River Nile, about 80 km from Kampala – Uganda's capital city – and nearly 600 km southeast of Kaabong.

Then, he paused, looked at me as if in anticipation of a comment but I said nothing until he mentioned that his biggest fear was that the Jie warriors would kill him.²⁷ He stated:

But no, I do not need pension, I am still a serving military officer and even Museveni, the president of Uganda, knows me... but no, I fear the Jie will kill me on the way...

It was at this point that one of his neighbours said: "... let him not waste your time, he is mad." The neighbour explained that all his life, LH-K-3 had never been a soldier. However, I told the neighbour that LH-K-3 was harmless and that I was interested in his story. All of a sudden, my words made LH-K-3 so elated and he talked resolutely:

Yes, *afande*, I am a soldier. I am a big man. I serve in the Uganda Army of Idi Amin. I am also a big man in the Uganda national liberation army [UNLA].²⁸

²⁷ The Jie are inhabitants of the north-western Karamoja district of Kotido, 73 km to the south of Kaabong. They are known to be a fierce fighting group.

Following this statement, he started becoming agitated. I decided to bid him farewell, promising to visit him again.

After two days, I visited him again in the afternoon. I found him at the entrance to his hut and he mentioned to me that he was being deployed by the military. He also mentioned that he had been an air force pilot of the UNLA and that frequently he piloted Colonel Omaria.²⁹ When I told him that I had heard about Colonel Omaria, he became excited and talked in a very sharp tone saying that while piloting the army helicopter he had been to the sky; that it was 93,000 km or a million miles from where we were standing in his yard. He said:

I was there. I saw only blazing objects...

He then paused abruptly and started walking away. I asked him to stay but he refused, saying he was hungry and going to look for *ngisilinga* [money]. When I gave him some money to buy food, he stood at full attention, saluted me and walked away.

As I walked out of the village, I met his neighbour, and inquired about LH-K-3's life. The neighbour said: "... just as I told you that person is my cousin and he is not well. He is mentally disturbed." He explained that LH-K-3 had been a powerful warrior about 20 years ago. He then talked about his cousin as someone who was once a very successful, rich and respected man. That he had also established himself as a very influential businessperson in their area. But he said that his cousin had a weak spot for women. In the process, he got himself many mistresses, one of whom was a poor man's wife. He then said that the poor man had complained and pleaded with LH-K-3 to leave his wife but regrettably, he did not listen. He stated that the poor man sought the help of a renowned *emuron* who "worked" on LH-K-3 [bewitched him], and that he had since been mad. "He finished him; he is wasted up to today. For his misdeeds, the *judge* [*emuron*] sentenced him for life", he added.

He said that although they [relatives] noticed LH-K-3's problems early enough it was not possible to help him because tradition dictates against adultery. He said:

²⁸ Idi Amin was Uganda's military ruler from 1971 to 1979. In 1979, the combined forces of the Tanzania peoples' defence forces (TDF) and the exiled UNLA invaded Uganda from Tanzania and overthrew Idi Amin. The UNLA then became the national army of the post-Amin government from 1979 to 1986.

²⁹ Colonel William A. Omaria served in the then Uganda national liberation front (UNLF/A) government as the Minister of State for local government.

Adultery is severely punished. But if the aggrieved party allows negotiation, then you will be fined not less than 150 cows. This is almost thrice the fine for murder.

He explained that since there was no room for negotiation and that nobody really sympathised with him, LH-K-3's situation got worse. Slowly, he started to sell off his assets cheaply and gave up managing his businesses:

... one day, my cousin shocked everyone when he sold his motor bike for only 10,000 Uganda shillings [five US dollars], hardly a tenth of its real price. He continued selling off his things until everything was gone.

He also pointed out that after LH-K-3 had become so poor, his wife left him and took all the children with her:

He has since lived as a helpless man, just roaming the villages while begging for food and money for cigarettes.

4.2.2.4. LH-K-4

A young woman in her mid-thirties but already widowed three times. I first encountered LH-K-4 at a local bar in her village where she traded in *kwete* (local sorghum beer) to earn her living. My guide and I had agreed to meet at the local bar to review our field plan for the following week. She seemed to have been listening in as the guide told me that he had received confirmation from "Major" that he had agreed to meet me the next day. LH-K-4, who was dressed in a yellow striped purple dress, a neckband of beads in bright and mixed colours, black rubber bands on her left arm and *amukat* (used car tyre rubber sandals), inquired with surprise:

Pardon me; is that our Major? That person is very notorious. He is so weird.

She went on to explain how one day "Major" almost killed her. The incident followed a "disagreement" between her and "Major" at the local bar. She said that he went out and she thought he had gone home only to see him reappear at the entrance of the bar with a gun. He shot at her but she miraculously survived the bullet. She explained that although she collapsed on the floor totally gripped in shock, "Major" just laughed off his act and told her:

You are lucky; it [bullet] was only one remaining. Had I three, by now you would be gone like those winds blowing.

She also said that the mere mention of the name “Major” reminds her and a lot of other people around the villages of Kaabong of the suffering they went through as the UPDF fought with “Major” and his group of warriors. Following her brief revelations, I asked to meet her for a life history interview and she agreed.

On the morning of Sunday 24 April 2011, I visited LH-K-4 at her home. She wore the same clothes I had seen her wearing the time we met at the bar. She lived with four of her children at her late parents’ home. There were six huts, all in one enclosure but only two of them were currently in use: the one where LH-K-4 and her children lived and another occupied by her sister-in-law. The huts, including those not being used, appeared well maintained. They all had fresh roof thatching and their walls had a new neat coating of cow dung. LH-K-4 said they had recently held the last funeral rites of her late mother. This perhaps explained why the huts had also been refurbished. Her uncle with four of his married sons lived in the next compound. She explained that the clan had allowed her to live in her late parents’ home because her father had been the head of the clan. Besides, she had a family of young children and she was a widow without help and a home to stay. Her only surviving brother had been forced to seek employment away from home. He lived most of his time in Moroto, nearly 120 km south of Kaabong.

While relating the story of her family, she said that she was the second last of eight children of her late parents. Three of her elder sisters were married and living with their families outside Kaabong. However, she told me how she would always remember 2004 as the year when they experienced a lot of pain and misery in their family. According to LH-K-4, the reason 2004 would ever be remembered was that it was the year when three of her elder brothers died, one after the other, at the hands of warriors. The warriors attacked and killed two of her brothers at home. Before long, another brother was also killed by the warriors in a raiding ambush on Kaabong Township. She said that two years earlier, in 2002, her first husband had been killed by warriors, forcing her to return to her parents’ home until 2004.

She described the situation then as too chaotic, dreadful and hopeless, particularly for ordinary people like her. Pointing to the rocks surrounding the village, she said that “Major” and his men [fellow warriors] used to hide in there. The soldiers used helicopter gunships and indiscriminately dropped shells with the hope that they would dislodge “Major” and his

group out of the rocks. This failed, but instead the shells would kill and maim many innocent people. She elaborated:

... one time our late father told us that that boy [Major] used to follow raiders and that is how he trained. He became very famous because of his tactics. He even trained other warriors and became a powerful warrior commander. He often drank in the local bars. But he was feared a lot, had a bad temper and could not tolerate arguments. People knew him as a commander of warriors but life went on until 2004 when he went into hiding.

She said that many people were displaced to the government hospital in the Township. The township was looted and people suffered because of lack of food and sleeping in the cold. According to LH-K-4, although there were other warriors, “Major” was the worst and most feared warrior ever known in their local community:

... without the machine [gun] he will never utter a word anyhow. He sits alone, quiet and very humble. But he has a very bad temper; he still has that bad heart.

During our second meeting, she spoke in detail about her own marital ordeals. She stated that after her first husband died in 2002, she was able to marry again. However, unfortunately, her second husband was also killed in 2004. In 2005, she married for the third time and lost her husband yet again; he was killed during a raiding mission. She tried to marry again but failed. She decided to migrate to Soroti town [about 250 km south of her home in Kaabong] but while there, her baby died of a mysterious illness. Then she was forced to return to her late father’s home with her four remaining children. That is where she has lived since 2007. She stated:

... I make a living by vending local beer...

Towards the end of the interview, LH-K-4 recounted to me her own experience of insecurity. She described 2004 as the worst time of her adult life. In her assessment, that time was the most terrifying and haunting because she had cheated death three times. She said:

I experienced a lot of suffering during that time. We were displaced as the soldiers battled the warriors. For several days, we had only water without food. You can imagine, I was breast-feeding, my baby almost died... and again my husband was killed.

Consequently, she told me that she believed her life could never be the same again:

Aah, the story of my life is full of misery and horror. Every other time these scenes keep coming to my head... I am not myself. I feel a lot of emptiness... I have to drink to just push on.

4.2.2.5. LH-M-5

On Friday 6 May 2011, as agreed, I called at the home of LH-M-5 for an interview. Earlier, LH-M-5 had shared with me a brief discussion about the customs and traditions of the Karimojong. LH-M-5 was identified by adult male focus group participants as the eldest and most knowledgeable person whom they often consulted on cultural issues whenever need arose. He wore an old grey jacket and a pair of torn shorts. On top of the shorts, he wrapped a *Suka* with green and yellow stripes. His feet were bare and his body looked physically frail. He could barely walk without the support of a walking stick.

Even though he shared the same compound with some of his wives, each of them lived in a separate hut. Part of the roof thatching of his hut was damaged and the mud all round the doorway had fallen off, leaving just bare wattle. A papyrus mat was suspended in front of the door, which he apparently used both as the shutter and as a curtain.

In our talks, he spoke in a frail voice, complained of *akoro* (hunger) while touching his abdomen and nose. I asked him whether he had a cold and he replied:

No, I am hungry and I am in need of snuff. Do you have some snuff?

Before I could reply him, he touched his nostrils and again said: "I need snuff." Therefore, I gave him some money and asked him to send for snuff. Immediately, he called his grandson and sent him to buy snuff. He then turned to me and said:

Well, I am 90 years old and I am head of this... clan. I had 10 wives but five have since died. Those still alive are very old; they are helpless like me. I was once a very successful family man. I had had many sons... umm, 15 of them but 13 died in the raids. The two who are living, I think in Mbale or Busia.³⁰ All my 17 daughters are married. I paid 150 heads of cattle to marry my first wife.

³⁰ Mbale and Busia are towns located further south east of Uganda at distances of 500 km and 480 km respectively from Kaabong.

He often repeated that he had once been a very successful family man and very wealthy. He also told me that for most of his life he had been a great herdsman:

I started herding when I was 13 years old and I did that until 2001. Then my herds were in hundreds and I had authority those days...

However, he said he was not the exception. He explained that those days the people used to have enough to eat; they had healthy and strong bodies and were very hard working:

I can tell you, the Karimojong then were a proud people...

He stated that since 2001, many people had lived under extraordinary stress. He told me about the several difficulties caused by insecurity such as people being robbed all the time. Yet it was so difficult to tell between the military and the raiders who was the people's enemy. He said that at least before that time, when the Turkana from Kenya used to raid them, they would follow, strike back, recover their animals and even steal more. So the raiders alone were not a big threat to survival and security because the people could maintain a balance through counter-raids. He disclosed that in 2004, the enemies attacked and killed six of his sons, including a nephew:

... yes, we had some guns for protection. And we were not as powerless and miserable as now. These days when the enemies come... they find the boys, they simply... tooo... tooo... tooo [shoot] and kill; that is how I lost my boys.

He said that since then they had lived unprotected and helpless. The enemies, especially the Turkana and Pokot from neighbouring Kenya, come to their village and took everything – chickens, goats, food and even household items, including women's beads. Worse still, he said that each time the UPDF responded to a raid, they would resort to torturing and arresting people instead of pursuing the enemies to rescue the stolen animals. He also said that at times the UPDF also looted. He added that even when the UPDF recovered the animals they seldom returned them to the rightful owners:

...UPDF usually comes after a raiding incident has happened... and only to add to our misery by looting and beating people. We have no hope for recovery... I am so worried about the young people. Imagine a man like me who once had countless herds, today there is not even a single cow as I speak to you.

He then remarked:

How can we be robbed all the time moreover at the hands of our would-be protectors?
As I speak to you now I feel so worthless that I have lost vitality... I am nothing.

He stated further that the people have since lived like beggars; that they are only kept alive by the WFP:

WFP is our saviour but the food is never enough. Many times, we also lose the food we are given to the enemies. In the end, some people just die quietly of hunger in their Manyattas.

He expressed a lot of fear and desperation when he said:

I think we are a cursed lot. How can we continuously live on handouts from outsiders? The fact that we have been reduced to beggars gives me too many thoughts.

4.2.3. Participants in conversations

Twenty participants (15 males, 5 females) out of 28 who participated in conversations (in-depth daily talks) were adults (see Table 5). Three of the adult males were *ngimurok* (traditional healers). Fourteen conversations with adults (11 males and heads of households, and 3 female spouses) were conducted at the *ere*/Manyatta level. Two conversations (1 adult male, 1 traditional healer) were organised and held at the kraal. The rest of the conversations (2 adult females, 2 traditional healers) took place in the market. The conversations were held between March and August 2011 and on average, conversations with each participant lasted an hour and 30 minutes.

Table 5**Summary description of adult participants in conversations**

Participant	District	Gender	Place of interview
CAM-M-1	Moroto	Male	<i>ere</i> /Manyatta
CAM-M-2	Moroto	Male	<i>ere</i> /Manyatta
CAM-M-3	Moroto	Male	<i>ere</i> /Manyatta
CAM-M-4	Moroto	Male	<i>ere</i> /Manyatta
CAM-M-5	Moroto	Male	<i>ere</i> /Manyatta
CAF-M-6	Moroto	Female	Market
CAF-M-7	Moroto	Female	<i>ere</i> /Manyatta
CAF-M-8	Moroto	Female	<i>ere</i> /Manyatta
CAM-M-9	Moroto	Male	Kraal
CAM-M-10	Moroto	Male	<i>ere</i> /Manyatta
CAM-M-11	Moroto	Male	<i>ere</i> /Manyatta
CAF-K-12	Kaabong	Female	<i>ere</i> /Manyatta
CAF-K-13	Kaabong	Female	Market
CAM-K-14	Kaabong	Male	<i>ere</i> /Manyatta
CAM-K-15	Kaabong	Male	<i>ere</i> /Manyatta
CAM-K-16	Kaabong	Male	<i>ere</i> /Manyatta
CAM-K-17	Kaabong	Male	<i>ere</i> /Manyatta
CTH-M-1	Moroto	Male	Market
CTH-K-2	Kaabong	Male	Kraal
CTH-M-3	Moroto	Male	Market

NB: CAM = Conversation with an adult male; CAF = Conversation with an adult female; and CTH = Conversation with traditional healer.

Eight children (5 males, 3 females) took part in the conversations held at the *ngierya*/Manyattas, playground, kraal and church. Five of the children (3 males, 2 females) were enrolled in school and three (2 males, 1 female) never attended school (see Table 6).

Conversations with child participants were conducted between March and May 2011.

Conversations with each child participant were structured into three or four brief sessions, each of which lasted about 15 minutes. Thus, the total amount of time spent with each child was about an hour.

Table 6

Child participants in conversations

Participant	District	Age	Gender	School grade	Place of interview
CMC-M-1	Moroto	11	Male	4	<i>ere</i> /Manyatta, playground
CMC-M-2	Moroto	13	Male	4	<i>ere</i> /Manyatta, playground
CFC-M-3	Moroto	14	Female	5	<i>ere</i> /Manyatta
CFC-K-4	Kaabong	14	Female	5	<i>ere</i> /Manyatta
CFC-K-5	Kaabong	15	Female	Not in school	<i>ere</i> /Manyatta
CMC-K-6	Kaabong	15	Male	6	<i>ere</i> /Manyatta, church, playground
CMC-K-7	Kaabong	12	Male	Not in school	<i>ere</i> /Manyatta, Kraal
CMC-K-8	Kaabong	13	Male	Not in school	<i>ere</i> /Manyatta, Kraal

NB: CMC = Conversation with a male child; and CFC = Conversation with a female child.

4.2.4. FGD participants

Twelve FGDs with adults (6 for men, 6 for women) and equal numbers (3 FGDs for men, 3 FGDs for women) in both study sites were conducted during March 2011 (see Table 7).

FGDs with men were relatively larger in size attracting on average 15 participants per group.

However, FGDs with women were smaller in size (average of 11 participants per FGD).

Given the context of forceful disarmament and decline in cattle raiding, this may suggest changing gender dynamics. More women than men are likely to be engaged in household activities aimed at livelihood sustenance. Group discussions with adult participants took an average of two and a half hours.

Table 7**Focus group discussion with adult participants**

FGD	District	Participants	Number
FGA-M-1	Moroto	Men	14
FGA-M-2	Moroto	Men	16
FGA-M-3	Moroto	Men	17
FGA-M-4	Moroto	Women	9
FGA-M-5	Moroto	Women	11
FGA-M-6	Moroto	Women	13
FGA-K-7	Kaabong	Men	16
FGA-K-8	Kaabong	Men	15
FGA-K-9	Kaabong	Men	15
FGA-K-10	Kaabong	Women	12
FGA-K-11	Kaabong	Women	10
FGA-K-12	Kaabong	Women	12

NB: FGA = Focus group discussion with adults.

Four FGDs were held with children (see Table 8) during March 2011. FGDs with children were held in Nadunget due to safety concerns and travel constraints linked to insecurity. This site was close to a military barracks and relatively secure, unlike Loyoro where violent conflict was ongoing due to raids. FGD 1 had 11 child participants (7 males, 4 females), FGD 2 had 13 (8 males, 5 females) and FGD 3 had 14 (10 males, 4 females). FGD 4 was the largest with 17 child participants (8 males, 9 females).

Table 8**Child FGD participants**

FGD	District	Participants
FGC-M-1	Moroto	11 (7 Males, 4 Females)
FGC-M-2	Moroto	13 (8 Males, 5 Females)
FGC-M-3	Moroto	14 (10 Males, 4 Females)
FGC-M-4	Moroto	17 (8 Males, 9 Females)

NB: FGC = Focus group discussion with children.

4.2.5. Key informants

In-depth interviews with key informants (KIs) were conducted with 19 individuals (see Table 9). Fifteen of these were males and four were females. They included five elders, three civic leaders, five district officials, two NGO/international agency staff, one official from ministry of Karamoja affairs (MoKAs), a Member of Parliament, and two staff from the ministry of health (MoH). Interviews took place over the course of five months between August 2010 and July 2012. The duration of each in-depth key informant interview ranged between forty-five minutes and an hour.

Table 9**Summary description of the key informants**

Key informant	Gender	District	Affiliation
KI-M-1	Male	Moroto	Ministry of health
KI-M-2	Male	Moroto	Parliament of Uganda
KI-M-3	Male	Moroto	MoKAs
KI-M-4	Male	Moroto	Civic leader
KI-M-5	Male	Moroto	Civic leader
KI-M-6	Male	Moroto	Civic leader
KI-K-7	Female	Kaabong	International agency
KI-K-8	Male	Kaabong	District official
KI-K-9	Male	Kaabong	District official
KI-K-10	Male	Kaabong	District official
KI-M-11	Female	Moroto	Ministry of health
KI-M-12	Male	Moroto	District official
KI-M-13	Male	Moroto	District official
KI-M-14	Female	Moroto	NGO staff
KI-M-15	Male	Moroto	Elder
KI-M-16	Female	Moroto	Elder
KI-M-17	Male	Moroto	Elder
KI-M-18	Male	Moroto	Elder
KI-M-19	Male	Moroto	Elder

NB: MoKAs = Ministry of Karamoja Affairs; NGO = Non-governmental organisation.

This sub-section has presented a description of the research participants and the context of their daily lives. It has also presented and described the different categories of research participants by data source. The next sub-section presents the results of detailed participants' thoughts describing conceptualisation of mental illness experienced by adults only.

4.3. Conceptualisation of Mental Illness in Adults only and Health-seeking behaviour

This sub-section provides an overview of the lay conceptions of mental illness in general, and presents the specific descriptions of mental illness in adults by participants and their notions regarding manifestations, aetiology, impact, prognosis and health-seeking for the different categories of mental illness.

4.3.1. An overview of lay conceptions of mental illness

As described in the methods section, a four-stage analytical model was adopted for the research. This entailed the triangulation of four different qualitative methods of data analysis: matrix master sheet, descriptive analysis, content analysis and thematic networks analysis. Using these qualitative methods of analysis in combination resulted in the identification of research themes as: (a) grand themes, (b) organising themes, and (c) sub-themes, respectively.

Seven grand themes emerged from the data. These were: (a) *ngikerep*, (b) *ngimasimas*, (c) *ngiwai wai*, (d) *akiyalolong*, (e) *akibwal*, (f) *ngibangibangi*, and (g) *akirakara*.

These local idioms of distress and analytical categories of mental illness will be discussed in more detail below. However, for ease of reference, a brief definition of each local idiom is as follows:

- *Ngikerep* is the local idiom for severe mental illness (psychosis) among adults who are thought to have “spoilt brains”.
- *Ngimasimasi* is the local idiom for severe mental illness that was recognised to present as foolishness among adults. In the context of this meaning of *ngimasimas*, afflicted adults were known to neither have the ability to understand nor to be in their “normal senses”.
- *Ngiwai wai* refers to severe mental illness that was known to occur in episodes. The illness was said to afflict adults who were known to present with confusion. Thus, afflicted adults lacked steadiness in their thoughts.
- *Akiyalolong* refers to mental illness experienced by adult sufferers that manifests through disturbances in feelings and thoughts. Afflicted adults were said to experience a lot of thoughts, sadness and worries.

- *Akibwal* is defined as mental illness that manifests in expression of negative emotions such as *aryangakin* (shock) and *apodo* (anxiety) by both adults and children. The expression of such feelings by sufferers was linked to their exposure to situations that cause terror, such as witnessing the torture and killing of other people.
- The local idiom of *ngibangibangi* refers to mental illness in childhood that manifests as an inability to think and understand things.
- *Akirakara* is a local idiom that refers to another typology of childhood mental illness. The illness manifests when afflicted children experience sudden and frequent falls and fainting or loss of consciousness.

At the intermediate level of analysis, five organising themes emerged from the data. These were: (a) manifestations, (b) aetiology, (c) impact, (d) prognosis, and (e) health-seeking. These organising themes were used in the analysis to integrate sub-themes that emerged from the data at the build up stage of analysis. The sub-themes represent the distinguishing features of the seven illness categories stated above. The sub-themes that comprise each of the five organising themes are described below.

The organising theme of manifestations of mental illness consisted of four sub-themes: (a) cognitive symptoms, (b) affective symptoms, (c) behavioural symptoms, and (d) somatic symptoms. The organising theme of aetiology of mental illness comprised three sub-themes: (a) supernatural factors, (b) biological factors, and (c) psychological and social factors. Nine sub-themes were identified and classified under the organising theme of impact of suffering mental illness. These were: (a) violence, (b) poor physical and mental health, (c) poor nutrition, (d) disability, (e) stigma, (f) marital and family breakdown, (g) premature death, (h) severe and relative deprivation, and (i) suicidal feelings. And that of prognosis of mental illness consisted of three sub-themes: (a) severe and chronic, (b) severe and episodic, and (c) acute and reversible. Finally, the organising theme of health-seeking comprised four sub-themes: (a) personal coping, (b) social support, (c) indigenous healing, and (d) bio-medical care. For ease of reference, a summary is presented in Figure 3, below.

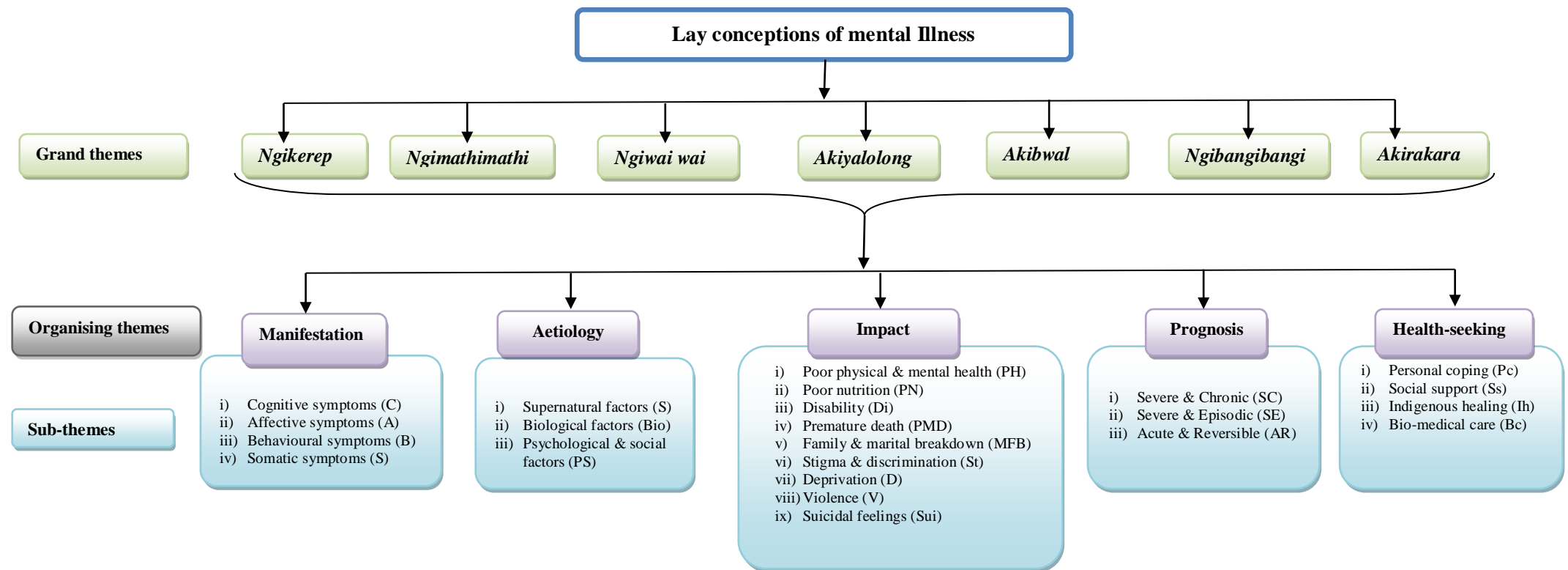


Figure 3. Conceptual model of lay conceptions of mental illness

4.3.1.1. Thematic synthesis

Using a thematic synthesis framework, I further summarised the themes and sub-themes concerning lay conceptions of mental illness. I developed the framework in two parts, which reflect the separate levels of analysis: grand themes and organising themes. The grand themes that refer to idioms of distress (or illness concepts) were synthesised into three main illness categories. These were mental illness experienced by adults (MIA), mental illness in childhood (MIC), and mental illness experienced by both adults and children. Secondly, in line with the grand themes, I synthesised the organising themes: manifestations, aetiology, impact, prognosis and health-seeking and their related sub-themes. Then, I integrated the grand themes and organising themes into a thematic synthesis of lay conceptions of mental illness. For ease of reference, a summary of the thematic synthesis of the lay conceptions of mental illness in relation to the reported manifestations, aetiology, impact prognosis and health-seeking is presented in Figure 4, below.

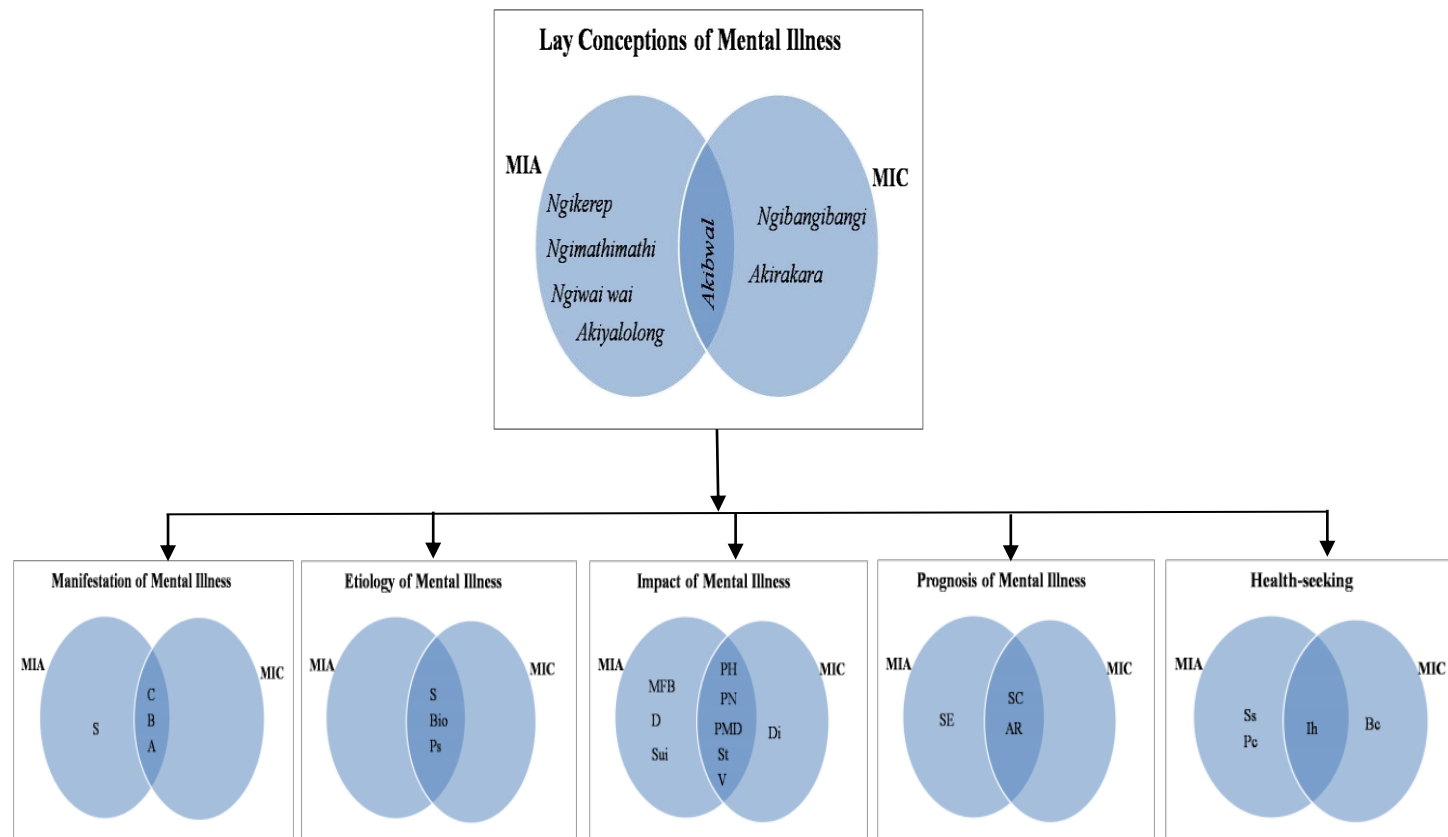


Figure 4. Thematic synthesis of lay conceptions of mental illness

Key: MIA = mental illness in adults; MIC = mental illness in childhood; *Akibwal* = mental illness experienced by adults and children

Manifestations: S = somatic symptoms; C = cognitive symptoms; B = behavioural symptoms; A = affective symptoms

Aetiology: S = supernatural factors; Bio = biological factors; Ps = psychological and social factors

Impact: MFB = marital and family breakdown; D = severe and relative deprivation; Sui = suicidal feelings; PH = poor physical and mental health; PN = poor nutrition; PMD = premature death; St = stigma; V = violence; Di = disability

Prognosis: SE = severe and episodic; SC = severe and chronic; AR = acute and reversible

Health-seeking: Ss = social support; Pc = personal coping; Ih = indigenous healing; Bc = bio-medical care

4.3.2. Terminologies of mental illness experienced by adults

Mental illness experienced by adults consisted of four lay categories of illnesses. These were: (a) *ngikerep*, (b) *ngimathimathi*, (c) *ngiwai wai*, and (d) *akiyalolong*. Below, I present the participants' thoughts describing the lay conception of each of the illnesses.

4.3.2.1. Ngikerep

Ngikerep, also described as *ngicen*, which means “the spirits of the dead”, was used to refer to one of the typologies of *edeke ka ekuwam* (“illness of spirits”) – the generic term for mental illness. Specifically, *ngikerep* (*ngicen*) refers to a major and most severe mental illness or psychosis. In this regard, an elderly woman informant, who earned her livelihood mainly through the sale of tobacco in the village market, said:

We call madness *ngikerep* ... *ngikerep* means there is something wrong with the way a person thinks and acts. In fact, this means the illness destroys the person's ability to understand. (CAF-K-13)

... the spirits of the dead enter your head and drive you away from others. You start to do things that are very different from what the rest of the people do. Then people will call you *itunganan ngini ikerepikinit* (person with *ngikerep*) ... (FGA-M-1)

Ngikerep or *ngicen* is the way we call it. It is as if you are possessed by spirits ... there is something wrong with the way you are thinking ... something has spoilt your brain ... Usually we say the brain is spoilt by spirits. (CAM-M-11)

These descriptions suggest that the participants recognised *ngikerep* (*ngicen*) as a mental health condition, affecting the brain.

4.3.2.2. Ngimathimathi

As outlined earlier, the participants named and identified *ngimasimasi*, which they also commonly referred to as *ngimathimathi*, as the second typology of *edeke ka ekuwam* (“illness of spirits”). The local idiom of *ngimathimathi* was used among the Karimojong to refer to the mental illness of foolishness:

... it is the mental illness of foolishness ... the mind is not working well that you cannot properly tell the difference between things in the environment around you. (KI-M-14)

... *ngimathimathi* is somebody who is mad ... that person is so foolish ... not in control of her senses, even though it ... is not worse than *ngikerep* [most severe mental illness] ... (CAM-M-1)

The participants' views revealed a recognition and identification of foolishness³¹ as a mental illness category. It was believed to manifest in an inability to understand things among adults, and that the mental illness of *ngimathimathi* was less severe than *ngikerep*.

4.3.2.3. Ngiwai wai

The local term *ngiwai wai* was used to identify a third category of *edeke ka ekuwam* ("illness of spirits") among adults. The term was used to describe an "illness of spirits" that occurs in episodes and manifests in confusion among adults. Hence, afflicted adults were also known to lack steadiness in their thoughts. The local term *ngiwai wai* was, however, used to name the illness as well as to label the afflicted individual:

... it is an illness of spirits that makes one to engage in senseless and funny behaviour ... it comes on and off ... like someone is operating on a knob that is turned on and then off ... but at times the person behaves well like others ... (FGA-K-10)

... *ngiwai wai* also means someone who is confused ... sometimes we use the term as an abuse for one who does things without thinking... (CAF-M-6)

4.3.2.4. Akiyalolong

The local idiom of *akiyalolong* was used to refer to disturbances of feelings and thoughts that adults often expressed when faced with everyday life difficulties. Citing loss of cattle to enemy raiders and death as common examples, participants said that adults faced with such difficulties often complained of having *ngatameta* (a lot of thoughts). Consequently, they also experienced *akiyoriwo* (sadness) and *akitam* (worries):

³¹ For ease of reference, the idiom of *ngimathimathi* will be used from now on to mean foolishness and to refer to people believed to be afflicted with foolishness.

... nowadays, many people say they have *ngatameta* (a lot of thoughts) ... the cows have been taken ... they are thinking day and night ... and that brings *akiyoriwo* (sadness) and *akitam* (worries) ... they develop it ... (FGA-M-1)

The terms *akiyalolong* and *ngatameta* were used interchangeably to refer to feelings and thoughts that were linked to experiences of sorrow and worries:

... we call that *akiyalolong* or *ngatameta* ... they come when there is a touching issue ... it bothers you so much that you feel worried and uncomfortable ... (FGA-K-10)

It was also used to express empathy for misery:

... in everyday talk, we say *akiyalolong* as a way to show sorrowfulness and to comfort one another ... such as when death has occurred in a friend's family... (CAF-M-6)

... when *akiyalolong* is there ... *jik jik* ... (constantly coming ... the minds are so troubled ... it is difficult to live happily or have good life... (FGA-K-7)

4.3.3. Manifestations of Mental Illness Experienced by Adults

The manifestations of mental illness experienced by adults were characterised by: (a) somatic symptoms, (b) cognitive symptoms, (c) behavioural symptoms, and (d) affective symptoms.

4.3.3.1. Somatic symptoms

Somatic symptoms were described as being only experienced by adults with *ngikerep*. Afflicted adults were described as engaging in four different forms of somatisation: (a) complaining of persistent hunger, (b) feeling so tired, (c) restlessness and refusal to eat, and (d) "blocked ears":

I think *akoro* (hunger) is one of the worst things that agitate an *ikerepikinit* (person with *ngikerep*) to behave in a violent manner. As he moves about, he seems to think of nothing else other than finding what to eat. Most times, you meet this person when he is calm; the only word he utters to you is *akoro*... as he touches the stomach. At first, he will mention it ... softly but eventually becomes so loud and irritating. (FGA-K-7)

A male elder stated that:

... when he is hungry, an *ikerepikinit* ... behaves so wild ... he forcefully demands for food ... should there be nothing; he becomes so hostile to the things around him ... he will beat pets like dogs ... even gets so furious at seeing just flies ... (CAM-M-9)

For the second form of somatisation of *ngikerep* (feeling so tired):

... it is a matter of fighting for life ... just a life of pain and suffering. They ... are involved in constant struggle without resting. That is how they get so exhausted and you find the person sleeping by the roadside ... (FGA-K-12)

Oh yes, the person walks away from home without purpose ... walks endlessly to no definite place ... In the end his feet get so badly swollen that he cannot walk anymore and simply falls down and lies under the hot sun very helpless ... (CAM-M-3)

The third form of somatisation of *ngikerep* was restlessness and a refusal to eat:

... the moment the person becomes so restless such that he refuses to eat and sometimes also fails to sleep then you know it is because of *anomoret apipilu* (too much pain) ... (FGA-K-12)

One participant made a link between having “blocked ears” and suffering *ngikerep*:

After 12 years of living together happily married, my partner started having episodes of bad headache during which he would also complain of “blocked ears”. He said it all started after he had a bad quarrel with an elder over sharing raided cattle. The elder accused him of rudeness. He tried to apologise but the elder refused to listen and instead swore to punish him. Indeed, a few months after that incident he would barely hear things. We consulted some healers but they said it was a curse. Sadly, he was not helped. The situation got out of hand when he soon became so violent until it was clear he had developed *ngikerep*. (CAF-K-12)

4.3.3.2. Cognitive symptoms

In describing the cognitive symptoms of mental illness experienced by adults, the participants stated that afflicted adults engaged in incoherent thoughts:

A person with such a serious mental illness... will tell you, ‘I am hearing someone calling out to me so loudly ... accusing me that I am not a good person ... I deserve only one thing, death. But I feel like I should die now. I am tired of someone telling me ...’ The person tells you all that and yet you do not see anyone or hear anything. (KI-M-11)

... some years back, we had a young man who was ... in town [Moroto] ... you would see him running and shouting, ‘... see that person chasing me ... he has a gun and he wants to kill me ... to shoot me ... help me before he finishes me’. (CAM-M-2)

Similarly, the participants thought that adults afflicted with *ngimathimathi* were unable to express abilities to understand, explain and remember things:

... *ngimathimathi* ... won’t know the difference between good and bad things. He cannot also distinguish which things are harmful from those that are harmless. Such difficulties tell you that he lacks sense of self-awareness. (FGA-M-5)

... when you see *ngimathimathi* ... within no time you will notice that there is nothing to show that he understands. (CAM-K-16)

... he cannot remember anything. Should you try to talk to him, the only thing he does is to simply stare at you. (KI-M-5)

Ngimathimathi was also believed to manifest through its sufferers experiencing communication problems such as incoherent speech and hearing impairment:

... she has difficulties of talking ... you can greet the person, how are you? The only sound that comes out of her mouth is, “Ah!”, as if to express surprise and that is all. (CAF-M-6)

For *ngiwai wai*, the participants said that afflicted adults demonstrated confusion during everyday interactions. Confusion was recognised by the failure of afflicted adults to exercise appropriate vigilance. However, not only did lack of vigilance manifest *ngiwai wai* but was also an indication of the inability to survive and not being socially responsible.

... *ngiwai wai* moves without a walking stick and neither carries a stool ... These are vital things that especially a man must have wherever he goes. To have a walking stick means you are alert and prepared for eventualities ... in case you are confronted. A responsible ... also carries own stool ... one way to show you are cognisant and respond to the difficulties of life ... we live in poverty ... *ngiwai wai* lacks such vigilance. (CAM-M-4)

... you find one who is wearing one pair of *amukat* (sandal) and when you ask them about what happened to the other pair, they won't know that it is missing and tell you where it is. (FGA-K-9)

4.3.3.3. Behavioural symptoms

The behavioural symptoms included violent behaviours and an inability to exercise self-care skills. There were, however, some variations in the ways these behaviours were recognised based on the nature of each specific illness. Adults with *ngikerep* and those afflicted with *ngiwai wai* were considered chaotic and violent. For example, the participants described the manifestation of *ngikerep* through violent behaviour as:

... *ikerepikinit* fights and disturbs other people ... talks a lot of nonsense ... insults people. You cannot know what goes on in her head ... one minute she will be talking to herself, the next minute she becomes chaotic and violent... (FGA-M-6)

... they ... roam about ... shouting and grabbing other people's things ... they scare and beat children ... (FGC-M-4)

... you find *ikerepikinit* doing things which others don't do ... carrying a dangerous weapon like spear. The person may also be dangerously carrying a baby as if going to throw it down ... singing and dancing alone ... things like that make other people to get concerned ... you cannot say that kind of person is in his normal senses ... there must be something ... (CAF-M-6)

... will remove clothes ... walk naked ... there are times she will be crying and running wildly. In the process, she also hurts people and talks obscene things ... (CAM-M-5)

... the person will eat own faeces ... You can tell a person who about to breakdown when people refer to her that she is about to eat her own faeces. At times, she defecates and smears faeces on herself. (CAF-M-7)

For *ngiwai wai*, it was stated:

...at times *ngiwai wai* ... sees where elders are seated and ... *paa, paa* (throws things) at them and distracts them ... upon reprimand, he says *mam, mam* (nothing, nothing) ... is forgiven (FGA-K-10)

The chaotic and violent behaviour of *ngiwai wai* was also linked to its episodic nature. Thus, the participants said that during times of presumed “normality” *ngiwai wai* showed dullness and were generally passive, non-provocative and least feared:

...during normal times, *ngiwai wai* has dull thinking ... is peaceful and causes no serious fear unless troubled ... (FGA-M-2)

Conversely, the behaviours of *ngimathimathi* afflicted adults were not thought to be violent although they at times also engaged in obscene things:

...he won't physically attack you but sometimes he says obscene words and does embarrassing things ... undresses before other people... (FGA-M-6)

Akiyalolong was recognised to manifest in silence and solitude:

...someone tends to *akililing* (keep quiet) ... sits alone ... and does not want to eat (*mam nyimuji*) ... (FGA-K-10)

The inability to exercise self-care skills in order to keep personal hygiene applied to *ngikerep*, *ngimathimathi* and *ngiwai wai*:

...*ikerepikinit* is always extremely dirty ... many times she will wear only a head band of rubbish ... feathers of chicken ... she will also eat non-edible things ... (FGA-M-6)

...ever dirty and smelling ... they never bathe ... (FGC-M-1)

Similarly, eating inedible things was part of *ngiwai wai*:

... when there is nobody to keep watch; *ngiwai wai* will eat bad and harmful things ... like those poisonous berries of *eligoi* and *ebuluka* (milk shrubs) that you see ripening in the hedges over there ... (FGA-M-1)

... umm, because of illness one will eat useless things ... rubbish ... things like waste already thrown away ... (CAF-K-13)

Additionally, the failure to exercise control over body activities was described as an indication of suffering *ngimathimathi*:

...someone suffering from *ngimathimathi* is not in charge of his body ... mucus will run down from the nose but he won't mind. (CAM-M-5)

...it is a sad and humiliating experience to watch an adult seated or lying helpless in one spot as he defecates or urinates on himself. (CAF-M-6)

However, participants also related that attribution of behaviours such as eating dirty things and bad body hygiene to suffering mental illness must be done with care:

...be careful with behaviours like neglected body hygiene and eating things thrown on waste heaps ... are common in Karamoja but not all the people who do that are sick ... they are normal ... a lot of people do such things ... are let down by lack of water ... soap and cannot find food. (KI-M-11)

... usually an adult has something to cover at least his or her ... but somebody who has that problem [mental illness] will not have anything ... also being dirty does not always mean illness ... most of us cannot afford basics like soap and as you can see water is so scarce... (FGA-M-6)

4.3.3.4. Affective symptoms

The affective symptoms that were described included worries, hopelessness, agitation, and anger. They were described as being particularly common among adults suffering *akiyalolong*, but were also present among *ngiwai wai* and *ngimathimathi*:

... apart from having a lot of thoughts, someone says they are feeling so low ... the spirit is so low because of *akitam* (worries) ... (FGA-M-4)

... in such a case there is *atametait ngina ka* (feeling hopeless) as one complains of *etau lopalang* (heart pain) ... (CAF-M-8)

... it is a bad feeling ... the type that makes you to have a lot of *angoit* (anger) ... you will feel so low and disturbed that you even start to blame yourself ... (CAM-M-3)

4.3.4. Aetiology of mental illness

The aetiologies of mental illness were described as belonging to three domains: (a) supernatural factors, (b) biological factors, and (c) psychological and social factors.

4.3.4.1. Supernatural factors

The attribution of adult suffering of mental illness to supernatural factors involved the influence of *akuj* (God), *atapapaa* (ancestor spirits), and *ngicen/ ngawuyonito* (the spirits of dead people or ghosts). Mental illness was also associated with malevolent acts of human or social agents: placing *ngilam* (curses) and *akisub l'thuam* (bewitchment). All of these were described as working in different ways to cause *ngikerep*. For *ngimathimathi*, causation was attributed to only three types of supernatural factors, namely, *ngicen/ngawuyonito* (the spirits of dead people or ghosts), *ngilam* (curses) and *akisub l'thuam* (bewitchment). However, the supernatural causation of *ngiwai wai* involved the influence of two specific factors – *ngilam* (curses) and *akisub l'thuam* (bewitchment). First, I will discuss aetiologies that were described as being exclusive to the suffering of *ngikerep*. These were characterised as *akuj* (God) and *atapapaa* (ancestor spirits). I will then present the participants' attributions of both *ngikerep* and *ngimathimathi* to supernatural influence of *ngicen/ngawuyonito* (the spirits of dead people or ghosts). Thereafter, I will describe supernatural influences that were said to act through the social dynamics of *akisub l'thuam* (bewitchment) and *ngilam* (curses) to cause the suffering of any of the three adult mental illnesses as outlined above. In addition, I will present what participants described as the reasons for the placing of curses by elders.

4.3.4.1.1. Ngikerep comes from akuj (God)

For most participants, there was consensus that *ngikerep* comes from *akuj* (God). They reasoned that *akuj* was the most powerful, and that all other forms of supernatural forces

derived their existence and power from him. *Akuj* was thus believed to be the source of life as well the determinant of circumstances of how people live their lives. The participants also believed that *akuj* was the one who grants people good health and by contrast the circumstances that caused people to suffer distress such as *ngikerep*:

... we are creations of *akuj* ... the most powerful of all. He decides how He wants each one of us to live ... he can bring *ngikerep* to a person or in family to alert people of his anger with them. (FGA-K-9)

Consistent with the group discussants' view, a key informant and female elder also attributed the aetiology of *ngikerep* to *akuj* (God):

... all of a sudden someone who has not had a known health condition becomes mad. As it is so difficult to tell the exact cause we think madness is from *akuj* (God). He is the one who knows how it comes and until it ends with someone's death. (KI-M-16)

Ngikerep was also said to come from *akuj* (God) only if there was no other aetiology suspected:

... we recognise madness as an act of *akuj*. Madness is interpreted as an act of *akuj* if there is no other cause associated with it. So the cause is totally unknown to anyone. So we say the sickness happened due to bad luck or bad omen from *akuj*. Or some people say it comes from the winds and it affects you. (KI-M-6)

4.3.4.1.2. Atapapaa (ancestor spirits)

For some participants, suffering *ngikerep* was also attributed to the influence of *atapapaa* (ancestor spirits):

... when spirits enter a person's head she becomes mad ... we say *aduwakou*; this means the head has knocked. The head stops working and a mad person cannot think of anything useful ... (FGA-M-4)

These spirits were said to turn malevolent for various reasons, such as one's failure to fulfil cultural and social obligations:

... in our communities we associate *ngikerep* to attack by spirits. There is a belief that *atapapaa* (ancestor spirits) are not happy with you. May be it is your grandfather,

grandmother who died, and you do not go to the grave to pray and offer sacrifices ...
(CAF-M-8)

A key informant described the religious beliefs and strong sense of connection to ancestral ties among the Karimojong as:

... I think we are people whom God has created with a strong will to endure. There are a lot of difficulties but we know how to live ... how to defend ourselves ... I am telling you ours is a unique tribe. You can leave us the way we are but we will survive. We believe that *akuj* heeds our pleas when we pray through our *atapapaa* (ancestor spirits). As I said the Karimojong traditional system is a unique one ... there are strict cultural norms and values that govern upbringing of children and how somebody should behave. It is the elders' role to ensure that the system works for our well-being. You must respect elders. They are our living *atapapaa* (ancestor spirits) and representatives of *akuj* (God). (KI-M-19)

The idea of relational properties between the living and their ancestors became more apparent when some participants related the aetiology of *ngikerep* to possession by ancestor spirits – a sign that the affected person is meant to assume the roles of *emuron/emurok* (traditional healer/diviner) in her community:

... for *amuronot* (someone possessed by ancestor spirits), ancestor spirits choose you as their medium to become *emuron/amuron* (traditional healer/diviner). Sacrifices and rituals should be performed. The spirits will come down and you get supernatural power bestowed on you. You will be among those to be managing this type of cases in future. Some people may say these are demons. But for us we say these are spirits that are visiting you. You are the choice of our ancestors. (CAM-M-11)

In addition, it was stated there was need to assess the family history of the person who is “spirit possessed” to find out if she comes from a lineage of *ngimurok* (healers). If confirmed, then she was taken through a process of initiation:

... there are people who come from the lineage of the *ngimurok* (healers/diviners). They become sick because they are possessed by spirits as a warning signal ...

calling. But checks must be done to ensure there is such as a thing in the family before one is initiated into a healer. (CAM-K-15)

Going through initiation was described as an important process that is intended for the initiate to learn esoteric knowledge of traditional healing from a practising and experienced healer. The *amuronot* (someone possessed by ancestor spirits) becomes an initiate, a status that enables her to acquire skills for managing her own illness and acting as a spirit medium who will offer healing services to others during her life. Initiation, therefore, serves to affirm the experience of an *amuronot* (someone possessed by ancestor spirits) and to instruct someone into traditional healing knowledge.

4.3.4.1.3. Ngicen/ngawuyonito (the spirits of dead people or ghosts)

Ngicen/ngawuyonito (the spirits of dead people or ghosts) were also implicated as supernatural causes of two of the mental illnesses – *ngikerep* and *ngimathimathi*. An *emuron* (traditional healer) stated that adult affliction with *ngikerep* caused by malevolent spirits was difficult to detect sometimes because of suspicion of spirit possession:

... it may come as a result of the work of *ngicen* ... from the wilderness. But because we must be sure that it is not spirit possession ... something that takes time ... if the patient does not respond to treatment then it is attacks by *ngicen* ... (CTH-M-3)

Unlike *ngikerep*, *ngicen/ngawuyonito* (the spirits of dead people or ghosts) were believed and feared to cause *ngimathimathi* through attacks on people who violate spaces where the spirits live:

... *ngicen/ngawuyonito* ... live in rivers, valleys, mountains and big trees. They will attack you if you go to those places ... you will suffer *ngimathimathi* the moment they enter your head. (FGA-M-2)

... some people have become *ngimathimathi* after swimming in the river during the rain. In our tradition, it is not allowed to go swimming in rivers when it is raining ... the time *ngicen/ngawuyonito* ... are very active near rivers and springs ... (CAM-M-1)

4.3.4.1.4. Akisub l'thuam (bewitchment)

The belief in *akisub l'thuam* (bewitchment) as a cause of each of these illnesses was evident in cultural and social explanations. Thus, adult suffering was linked to manipulation of *akapil* (witchcraft) by social agents. For example, the main intention of sending *akapil* (witchcraft) to afflict a victim with *ngikerep* was to punish them with death or for them to become worthless:

Nobody should tell you a lie. There is a lot of *akapil* ... in Karamoja. People may not want to freely talk about ... but it happens. *Akapil* ... is part of our survival ... *akiyar* (life). If someone feels so much wronged and cannot fight back directly they will go and ask *emuron* (traditional healer) to make the wrongdoer to suffer death or *ngikerep*, in case of anything less ... you will only get to know this when you go to divine and *emuron* tells you the *ikerepikinit* (person with *ngikerep*) was made to eat herbs or walked over them and that is how she got finished off [bewitched] ... (FGA-M-4)

Moreover, *ngikerep* was associated with *akisub l'thuam* (bewitchment) because of uncertainty about its exact origins, strangeness, and lethal nature:

... unlike other diseases which come by themselves, *ngikerep* does not catch someone just like that. It is a deadly and strange illness ... there must be something ... for someone to get it ... there must be something ... wrong with you and your family. (FGA-M-3)

Like *ngikerep*, the suffering of *ngimathimathi* and *ngiwai wai* was also linked to moralised familial relations. As much as *ngimathimathi* and *ngiwai wai* were thought to be less lethal than *ngikerep*, participants stated that often problems within families led to acts of *akisub l'thuam* (bewitchment). Hence, acts of *akisub l'thuam* (bewitchment) were explained at two levels. Firstly, bewitchment was believed to be due to jealousy. *Akisub l'thuam* (bewitchment) was also interpreted to be an act of revenge, especially by powerless people who felt they had been wronged but had no other way to seek redress. In both cases, however, the services of *ngimurok* (traditional healers/diviners) were sought:

We suspect envy by others if the *ngimathimathi* (person afflicted with foolishness) has not had a history of misconduct. In that case, the common talk in the village will

be that of *akiroga-irogatae* (he has been bewitched) or *itiyatae e'*Tom (Tom is finished). (FGA-K-9)

... it is interpreted as being bewitched or charmed. There are wrong people who look at you with a bad eye. They do not wish you well ... just want to see you helpless ... (CAM-M-3)

Bewitchment was also seen as an important weapon of dealing with distress resulting from abrupt loss:

For powerless and helpless families, they fight back using *akapil* ... In case you are wronged and you go to *emuron* (traditional healer), he will ask you, 'What do you want the person to be?' You will say, I want him to be ... you can even ask for death if the damage done to you cannot be corrected such as death. (CAM-M-1)

Participants stated that one purpose of *akisub l'thuam* (bewitchment) was to afflict someone with *ngimathimathi* in order to avenge the harm, misfortune and distress that the person was believed to have caused to another person. And, *ngimathimathi* was a preferred form of vengeance since it incapacitated the ability of the sufferer to fight back – the afflicted person was made to suffer and yet lacked the means to retaliate:

... in the past if you killed, you were also killed and that settled the matter. It is different today because of fear of being charged for murder. There is also the fear and frustration of going through the formal court system without solving disputes quickly. That way, people are forced to turn to *akisub l'thuam* ... as the short cut to seeking justice. It ... also leaves a lasting mark on the enemy. (FGA-K-10)

People were also punished to suffer *ngimathimathi* by *akisub l'thuam* (bewitchment) for failure to pay customary reparation for murder:

... those days if you killed someone by accident, it was allowed to compensate ... it ranged between 30 and 60 cows. Then you had to be taken through rituals to cleanse you. Things have changed these days; people do not have those many cows for them to do that kind of thing ... instead, you hear someone has been bewitched. (FGA-M-5)

As in the case of both *ngikerep* and *ngimathimathi*, the urge to avenge distress drove aggrieved parties into using *akapil* (witchcraft) to afflict their enemies with *ngiwai wai*. But usually *akapil* (witchcraft) was used to respond to large scale suffering of a communal nature such as loss of family land:

... the powerful and wealthy may decide to grab the land of poorer people. That means a communal loss because here land belongs to families ... an act of that nature forces people to use disguised means such as *akapil* (witchcraft) ... and you see results of that through an illness of such nature ... on the other side ... (FGA-K-7)

The potential targets of *akisub l'thuam* (bewitchment) were moreover not only the immediate enemies but also their agnates. This was intended to weaken and cut off possible retaliation through social support from such relations:

... in a way, every close male kin are a potential target ... the motive is to make sure that they will not be the ones to fight back in future ... (FGA-K-7)

... males are possible targets because they are the ones usually at the centre of those things ... fighting for land ... although in the end other people like women also suffer. (CAF-M-8)

The need to settle scores and jealousy were seen as the key drivers for people who engaged in the practice among the Karimojong.

4.3.4.1.5. Ngilam (curses)

Elders were described as being respected and feared and important people. They are believed to intercede in difficulties of everyday living. As such, they have powers to curse:

Here we believe in elders ... they are our mediators with *akuj* (God). Elders are special people who solve many difficulties of life ... they are the source of all blessings ... you must never joke with them and annoy them but always show respect to them ... if an elder says, *alamit ayong eyon* (I am cursing you) it happens and you will become *ikerepikinit* (person with *ngikerep*). (FGA-K-7)

At the level of the individual, experiencing persistent psychological distress could also be interpreted as possible punishment. This was believed to happen when a person suspected that she probably fell short in fulfilling her moral obligations:

You know if you develop a mental problem, you try this or that to solve it. If none of the things you have tried helps you, you are left with no option but to think that may be this thing is getting me because I did something bad ... there must be something wrong. (CAM-M-4)

For *ngimathimathi*, *ngilam* (curses) were said to be the most common aetiology of the illness:

... should a normal adult start doing childish things and behave helplessly like playing in the mud and lying under the hot sun miserably, the first thing to suspect is a curse. (FGA-K-11)

The belief in *ngilam* (curses) as the cause for adults suffering *ngimathimathi* was also emphasised by participants who explained that:

... a curse comes in when a person starts doing surprising things that are least expected of his age ... that shows he has problems with his mind ... (FGA-M-3)

Sufferers of *ngiwai wai* were considered to be the victims of *ngilam* (curses) placed on one of the parents and that run in the family for generations:

... for *ngiwai wai*, some people get it as long as there is *ngaronon* (a curse for the whole family) ... this means that someone in their lineage had the illness due to a curse ... (FGA-K-8)

... it is not like that ... the thing is that if the illness occurs in one generation after another then there must be something ... a curse in that particular family ... that is the way we look at it ... (FGA-K-8)

Apart from attributing *ngiwai wai* to familial curses, they were equally associated with other misfortunes that happened in families. For example, some families were thought to experience persistent feuds and to fail to raise sufficient herds of cattle because of *ngilam* (curses):

... for a Karimojong, a good family is identified with the wealth of large herds of cattle ... that is a sign of both good life and peaceful living among relations. It is not the same thing in a cursed family; relations do not work together and have no peace ... it is a life of feuds and enmity always. (CAM-K-15)

4.3.4.2. Reasons for placing curses

The reasons for placing curses included failure to respect elders, failure to live to societal expectations, enforcing cultural loyalty and promoting social mutuality. Others included transgression of cultural taboos and desecration of shrines, as well as doing shameful and disgraceful things.

4.3.4.2.1. Failure to respect elders

The main reason for placing curses was said to be the failure to show respect to elders:

... you know the cultural institution in Karamoja is still very strong. The elders still have a lot of power ... if you defy an elder then you are cursed and you are bound to have *ngikerep*. (KI-M-16)

The elders were believed to place *ngilam* (curses) on people to suffer *ngimathimathi* as a culturally sanctioned means to assert authority and social control. In explaining the cultural significance of the tradition of curses among the Karimojong, the participants stated that through curses elders were able to assert and uphold their authority as well as remind others of the trust vested in them by society:

For the elders anything that they decide to *akilam* (curse) will be *ilamam* (cursed) forever. That power is entrusted to them. They do that on the behalf of everyone in Karamoja. It is important for good health, good relations and survival amidst the many difficulties we face in life. (FGA-M-1)

Apart from elders placing intergenerational curses that caused *ngiwai wai* to run in families, they were also recognised as *ngimurok* (traditional healers):

... yeah, in such cases elders say that the one suffering from it got the illness because of a problem [curse] in their family ... most likely someone saw *emuron* (traditional healer) who agreed to punish the family with the curse ... so that is how it [*ngiwai wai*] keeps coming up in their blood ... (CAM-M-2)

A key informant stated that while the knowledge of familial curses in relation to suffering the misfortune of *ngiwai wai* was sensitive and secretively kept, elders learnt of such things through consultations:

... you know things of that nature are sensitive and usually well kept secrets ... but I think out of desperation people in such families consult with elders with the hope and feeling that there could be a way to help them to fix the problem and stop the predicament ... (KI-M-17)

4.3.4.2.2. Failure to live up to societal expectations

While the failure to respect elders was believed to stir up their anger to use *ngilam* (curses) to cause the affliction of *ngikerep*, *ilama* (cursing) also had other moral dimensions related to it. One of these was the failure to live up to societal expectations. In this context, *ngimathimathi* afflicted people were thought cursed because of their inability to diligently and properly perform social roles and responsibilities assigned to them:

... our culture, authority is in the hands of elders. They are in charge of all matters of society and they must ensure that things are going well. Should you stubbornly dodge your obligations elders will curse you. (CAM-M-11)

... it goes nowhere but to your head ... you are *ilamam* (cursed) for *ngimathimathi* for letting down others. (CAM-M-10)

4.3.4.2.3. Enforcing cultural loyalty

Likewise, the fear of being *ilamam* (cursed) was considered important for enforcing cultural loyalty:

... you must never betray your people. Such action disturbs peace and order and you will be *ilamam* (cursed) ... *ngimathimathi*. Now, let me tell you one instance that happened of that kind. Once a man plotted with enemies to raid his own. Although they succeeded, the rest of the people became aware that he had betrayed them. The elders were so much infuriated that they cursed him ... he has suffered from it since then. (KI-M-17)

4.3.4.2.4. Promoting social mutuality

Another moral dimension of *ilama* (cursing) or use of threats by elders to curse someone to suffer *ngimathimathi* was to promote a sense of social mutuality in society:

... should the clan send you to represent them at *akiriket* (sacred assembly for the elders), then you act contrary to the wishes of the elders ... they will work on you ... so that the others can learn from your example. (FGA-M-1)

Through issuing threats of *ngilam* (curses) and perhaps doing the actual *ilama* (cursing), some elders also exposed themselves as culprits of moral failure:

... elders decide to *akilam* (curse) you when you do something wrong ... in our culture elders can tell you to kill a bull and there are parts meant for them. If you do not serve them those parts some greedy elders can decide to *akilam* (curse) you. Also, if you are a person on the village who is so notorious, the elders will discipline you by *ilama* (cursing) you. (CAM-K-17)

4.3.4.2.5. Transgression of cultural taboos and desecration of shrines

Participants also described elders placing curses on individuals for transgressing cultural taboos and desecrating sacred places:

... in our culture, *ilama* (cursing) often happens for two reasons. You can be *ilamam* (cursed) for breaking cultural taboos such as stealing, adultery, incest and not respecting elders. You will also be *ilamam* (cursed) for defecating in a sacred place like a shrine ... under a tree designated for clan meetings and rituals. In that case, *ilama* (cursing) serves to punish the offender for her offences committed against society. (KI-M-6)

4.3.4.2.6. Doing shameful and disgraceful things

Elders were also said to engage in *ilama* (cursing) people for doing things that brought shame and disgrace on society:

... you get it [*ngimathimathi*] for actions like *atikonor* (rape), *elomanu* (adultery) and incest. These break cultural taboos. Such things are not allowed ... hurt others by bringing a lot of shame and cause hatred and bad relations among people. (FGA-K-12)

While explaining the experience of psychosocial distress and social stigma by victims of sexual violence in Karamoja, female group participants said:

... whenever a girl or mother is raped, her worst fear is to get pregnant ... it disturbs her so much that she is going to carry the child of a man she does not know ... an enemy of her people and she will be blamed for it. There is no other man on the village who can accept to marry such a girl ... adultery or rape for the married woman means the end of her marriage ... no more hope for survival. (FGA-K-12)

Some participants thought that curses were used as a last resort:

... *ilama* (cursing) is one of those last things elders will decide to do to punish wrong doing. It is when you hurt others but fail to make amends with them. (CAM-K-15)

... often times, many elders restrain from placing *ngilam* (curses) on others for once you are *ilamam* (cursed) that means you will live with it ... that may also be the case with your offsprings. That is bad luck that is too complicated and feared among us the Karimojong. (CAM-K-17)

4.3.4.3. Biological (bio-medical) factors

The role of biological (bio-medical) factors in the suffering of mental illness was seen as exclusive to *ngiwai wai*. However, these factors were not considered sufficient to cause the affliction. Rather they were seen as indications that enabled people to understand the expression of the affliction.

Physical illness such as *elekes* (malaria) was associated with onset of *ngiwai wai*, but only if it failed to respond to treatment. The participants explained that it was easy to cure using herbal treatments, and that these treatments were usually available. The failure to recover from *elekes* (malaria), therefore, was an indication that the afflicted person suffered from a more serious illness believed to be *ngiwai wai*:

... in some cases *elekes* (malaria) comes first and then it is followed by *ngiwai wai*. But that happens if it [*elekes* (malaria)] refuses to go ... you know we have no hospitals but we are living because of our herbs. *Akuj* (God) gave us that knowledge; pastoralists, herbalists, we are living ... if *elekes* (malaria) fails to respond to herbal treatment then we know ... there must be something ... (KI-M-19)

The link between hunger, which was referred to as *akoro*, and suffering *ngiwai wai* was indirectly made by the participants when they said that *akoro* made people hostile:

... no, no; not only that ... you should first know that *akoro* (hunger) is a common problem ... it has been with us for long ... our cows have been stolen ... and there are no guns to ... rebuild or increase our herds ... nowadays *akoro* has become so intense ... because of starvation some of us have lost all senses ... (FGA-K-7)

In terms of substance (ab-) use, a combination of excessive drinking of *kwete* (sorghum beer) and sniffing *etaba* (snuff-tobacco) were thought to trigger and exacerbate *ngiwai wai*:

... here in Karamoja you cannot avoid taking *kwete* ... it is our food and *etaba* (doing snuff) is cultural ... is supposed to make one refresh the “mind” ... But if that problem exists they can make it worse ... (FGA-K-10)

... drinking *kwete* and snuffing are cultural ... although someone like *ekimera* (an alcoholic) can have difficulties with them that can make him mad ... (KI-M-16)

The idea that *ngiwai wai* could be transmitted through genetic means was implicitly expressed:

... some families have a history of *ngiwai wai* ... so you can say it is in their blood ... but also if one family has been associated with *ngiwai wai* ... it can attack them any time during the course of their life ... (FGA-M-3)

4.3.4.4. Psychological and social factors

The experience of *akiyalolong* was associated with the influence of psychological and social factors that cause emotional pain and social distress respectively. The psychological factors are frustration and grief.

Emotional pain in the form of grief and frustration brought about by the death of a breadwinner in a family and perceived to cause *akiyalolong* was described:

... there are women who become widows at a young age after their husbands go raiding and never to come back ... they tend to suffer a lot of emotional pain ... the frustration is much bigger because there is no one to ensure the family will have access to milk and blood for food ... (FGA-M-3)

Further, a participant drew the connection between feeling emotional pain, affliction with *akiyalolong* and suicide as:

... we saved a young woman from ending her life ... she had been raped by a neighbour ... she said that the morning it happened most people had gone for *ikwa lounoi* (food for work). The man sneaked into her hut and forced her down ... the elders tried to persuade her husband to understand but he refused to listen ... he called her a prostitute, blamed everything on her and demanded to have his cows [bride wealth] back ... she said that for days she had been constantly thinking about the humiliation ... rejection and ... that she thought she had no reason to live ... (CAM-M-2)

The social factors include loss of livelihood, deprivation, hunger and social rejection:

... there have been cases of people who cannot cope with very stressful situations of sudden loss ... the commonest cases are those of men who lose their entire herds ... it is as a result of dropping from being self-reliant to a nobody ... it is that shame and frustration that ... (KI-M-6)

... it is difficult and hopeless life ... we are crying at night because of enemies ... the UPDF do not fight at night ... they wait until morning then they will come ... give us the gun ... give us the gun as they beat you ... after they even take the few cows that would have remained ... you are hopeless and thinking too much ... (CAM-M-9)

Exposure to deprivation and failure to access social support were dynamics described as “double misfortune” that made the elderly particularly susceptible to *akiyalolong*:

... some of our elderly people get the illness because they are faced with double misfortune ... extreme poverty and yet cannot get help from anyone ... the children and some of their relatives from whom they may have received help, might all have “disappeared” [died]... (FGA-M-2)

The experience of hunger was linked to *akiyalolong* as people, particularly men, were said to suffer loss of self-esteem because of change in gender dynamics:

... these days many men don't feel they are husbands ... women have taken over their roles ... they are the ones authorised to receive food [aid] for the family ... how can you be a man ... when you depend on a woman ...? (FGA-M-2)

4.3.5. The impact of mental illness

The impact of suffering mental illness was believed to affect not only individual adult sufferers but also their families. Affliction with mental illness also negatively impacted social relations within the wider social structure of society. The impacts were: (a) violence, (b) poor (physical) health, (c) poor nutrition, (d) stigma, (e) marital failure and family breakdown, (f) premature death, and (g) deprivation in varying degrees of severity for adults with *akiyalolong*. In addition, the experience of *akiyalolong* was also known to result in suicidal feelings. First, I will discuss the phenomenon of violence since it applied to all the typologies of mental illness suffered by adults. Then, I will discuss the impacts of affliction that were exclusive to *ngikerep*, *ngimathimathi* and *ngiwai wai*. Finally, I will describe developing suicidal feelings as an impact associated with only the affliction of *akiyalolong*.

4.3.5.1. Violence

Adults were reported to engage in acts of violence because of mental illness. Sufferers of *ngikerep* and *ngiwai wai* were considered more violent than those afflicted with either *ngimathimathi* or *akiyalolong*:

... that person is not *ejok* (normal) ... does things without any sense of direction; you can say the person has lost all her senses ... she can harm you and do any of those bad things ... (FGA-M-2)

There was however also a sense that an *ngimathimathi* afflicted adult may engage in acts of violence:

... he can be a nuisance but does not disturb most times ... *ngimathimathi* is not as much feared as an *ikerepikinit* ... (FGA-K-11)

4.3.5.2. Poor (physical) health

Ngikerep, *ngimathimathi* and *ngiwai wai* were said to significantly destroy the afflicted people's abilities to ensure good health:

... how do I explain this one? Okay, imagine seeing someone who is mad ... I am sure you cannot see any sign of good health in that person. That person cannot care for himself. He is just too dirty to be normal [healthy]. It is a life full of pain. His body has a lot of injuries and scars, as he is hurt when he fights or is beaten by others. The skin turns pale with rashes all over the body. I believe the person frequently gets *elekes* (malaria) but who cares ... you know most people believe that a mad person does not understand. (CAM-M-10)

4.3.5.3. Poor nutrition

Besides suffering poor (physical) health, it was also noted that poor nutrition negatively impacted the well-being of adults with mental illness. Participants noted that despite the widespread food distress people faced, an *ikerepikinit* (person with *ngikerep*) suffered more than others because of lack of access to food resources:

Here in Karamoja, everyone struggles to find food, children and adults alike. The lucky families can manage only a meal in a day. Everyone in the family must work. But a mad person does not work. There is nothing to expect from that person and so in most cases there is nothing [food] received in return. That is how they end up picking this and that. They eat anything they lay hands on. Sometimes, they eat poisonous things that kill them without knowing. (FGA-K-9)

The experience of poor nutrition by the *ngiwai wai* was linked to the episodic nature of the illness. In this regard, the participants stated:

... during times of severe attack *ngiwai wai* refuses to eat food or eats very little ... often that may go on for several weeks making the person to become frail ... (FGA-K-9)

4.3.5.4. Stigma

The issues of stigma and discrimination of adults with severe mental illness (*ngikerep*, *ngimathimathi* and *ngiwai wai*) were discussed at two levels. First, participants discussed stigma and discrimination of afflicted adults in the context of society's attitude towards them. Secondly, they were discussed in relation to how the experience of severe mental illness in a family impacted social relations within the wider social structure of Karimojong society:

... we think of an *ikerepikinit* as an outcast ... very few people really feel for such a person. That is why you find that person removes clothes and walks naked but people are not bothered ... even those who would help fear to be harmed ... (FGA-M-6)

People with *ngikerep* were regarded as socially disordered, thought to lose their humanity, value and dignity, and subjected to a life of social exclusion:

... that is a no person. With time, people just forget that someone lived ... there is nothing to remember that person for ... in most cases when someone like that dies they leave nothing that other people can inherit ... not even a child ... there is nothing to show for their entire life on earth. (FGA-M-4)

... usually we talk of a *nangikerep* (female person with *ngikerep*) as an *akaakiding* (useless female person) and a *loangikerep* (male person with *ngikerep*) is an *ekaakiding* (useless male person). Think of a person who does not understand anything; just makes funny signs, sleeps anywhere, carries useless things as though they are useful and only survives by the grace of *akuji*. (KI-K-7)

... people won't care that much. They will abuse you that you are nothing ... like you are garbage of sorts. (CAF-K-12)

In terms of how the experience of severe mental illness in a family impacted on social relations within the wider social structure, suffering *ngikerep* was seen to be symbolic of an important cultural mechanism – one intended to administer social sanctions directed at the sufferer and her family for their bad morals and anti-social conduct in society:

In Karimojong culture, we believe that an *ikerepikinit* ... is likely to be somebody who was a wrong doer ... you will hear people say that one must have been punished for bad manners ... punishment for having 'a long hand' [stealing] or for disobeying elders ... take it that *ikerepikinit* or her family must have been bad people. (KI-K-8)

The experience of *ngikerep* in a family also resulted in strained social relations that might have contributed to perpetuating social stigma of the sufferers and their families:

... people always feel that the family and relatives of an *ikerepikinit* have bad hearts ... they do evil things to others. In fact, a family like that is very much feared and

held in a lot of suspicion ... on many occasions, the family is not invited to attend cultural festivals like the *akiriket* (sacred assembly for the elders) ... and, you know the most important decisions are made during the *akiriket*. Apart from that people will avoid to marry from a family with a history of *ngikerep*. (FGA-K-12)

Similar feelings were expressed towards people with *ngimathimathi*:

... the major issue is bad morals. People know it is *akilam* (curse) or *akisub l'thuam* (bewitchment) because of being a thief or it is adultery or cheating ... once the illness strikes, people look to those kinds of things for answers. (FGA-K-12)

Yet, because the *ngimathimathi* were considered too incompetent to live without the support of other people, they were denied participation in leadership. For example, despite one's age and seniority, once afflicted with *ngimathimathi* one would never be recognised as an elder:

... impossible, that person is useless. How can he become an elder? *Ngimathimathi* means loss of *aosou* (wisdom). *Aosou* (wisdom) of all things is what is most expected of an elder. But with *ngimathimathi* you won't have it [*aosou* (wisdom)]. Without *aosou* you cannot make decisions and advise others. (FGA-K-8)

4.3.5.5. Marital failure and family breakdown

Marital failure and family breakdown were linked to suffering severe mental illness by adults, although the specific impact depended on the nature of illness. For example, the onset of *ngikerep* for a man who had his own cows meant total disaster for him and his family. He loses all the means for making a livelihood, including the wealth, prosperity and fame which cows are known to bring to a Karimojong man's home:

... that sickness ... is terrible ... should a man get it, that is the end of him. That means a life full of chaos and complete ruin ... nothing good comes out of it. Everything is lost ... the cows will be stolen and once they are gone there is nothing like good life thereafter. It is worse for a married man because his wives will also leave him for he can longer protect them and provide for them and the family will be gone. (CAM-M-4)

Like afflicted men, women with *ngikerep* also lose everything that would guarantee a future in Karimojong society. The two most important aspects that defined an adult female's life

were mentioned as getting married and having children. Therefore, a female who suffered *ngikerep* was considered to be social liability:

We know it very well that a woman with *ngikerep* never gets married. She cannot keep a home in order to produce children. You know as children grow they also bring in more cows in the future. That ensures the prosperity of a family. No man can waste cows on a woman who has a bad illness like that ... because she does not have any future to talk of ... (KI-M-16)

In contrast, a participant stated that if it were the female spouse that suffered *ngimathimathi*, the husband would eventually neglect her and then marry another wife:

... initially, many things are tried and when everything seems to fail she is left on her own. Then as long as he has the cows, the man has to find another woman to marry. (CAM-M-9)

4.3.5.6. Premature death

Participants reported that many people with severe mental illness often died prematurely.

Premature death seemed more frequent among people with *ngikerep*:

The moment a person gets *ngikerep*, it is very difficult for that person to live for long. Death comes from many things: accidents, poisoning and hunger, together with ordinary sickness. But it is difficult to tell which exact place that person dies from. Suddenly the person disappears and you may think she lives in another place when actually she is dead. (FGA-M-6)

... people with *ngikerep* usually die from diseases which can be cured like *elekes* (malaria). Their bodies become weak because of the many problems caused by a head that does not work. (CAF-M-6)

4.3.5.7. Deprivation

Participants said that because of their inability to work and live a productive life, people with *ngikerep* were the most severely deprived among a population living in extreme poverty:

As you can see, we are very poor people. We would not be alive if there were no cows. A cow is the mother and father of a Karimojong. Nobody can give a mad son cows. They are of no use to him. There is no need to waste cows on a man who

cannot bring cows to the kraal. So an *ikerepikinit* ... cannot own cows. It is just impossible. (FGA-K-8)

According to the participants, both people afflicted with *ngimathimathi* and those suffering *ngiwai wai* become dispossessed and extremely poor due to illness. Consequently, not only were they deprived of their livelihood and lost their autonomy but also had no opportunities to live a good life:

... the cows and all property will be stolen or forcefully taken by enemies [raiders] ... life becomes so difficult for them. In the end, their situation becomes so unbearable because they have no means by which to live, that also makes their illness worse, and they live without purpose. (FGA-K-9)

On the contrary, while *akiyalolong* was said to result from sudden loss of wealth and means of livelihood, amongst others, its experience was thought to drive people into relative deprivation. This was especially the case when the affected persons failed to quickly access mutual support from others in order to rebuild their lives:

... that happens as someone may take long to overcome the loss he has suffered ... too much thinking takes a toll on his energies that he fails to work in the meantime ... and life is worse if he sees nothing forthcoming as help coming from his kin ... (KI-M-6)

4.3.5.8. Suicidal feelings

The participants identified the tendency to develop suicidal feelings as one of the major impacts resulting from adults' exposure to the psychosocial distress of *akiyalolong*. For example:

... not many people have "big hearts" and can tolerate a lot of troubles ... and I think it is fear that causes people with troubled thoughts to think of killing themselves ... (CAF-M-7)

... suicide cases are common particularly among women ... besides raiders attacking and looting everything, they also destroy whatever they cannot take and even kill their husbands. That is how women give up ... (CAM-M-5)

4.3.6. Prognosis of mental illness

The prognosis of both *ngikerep* and *ngimathimathi* was said to be severe and chronic:

... *ngikerep* is the worst madness we know of in Karamoja ... so serious that it makes the affected person become a total nuisance ... how you wish there was never a person like that in the community ... (FGA-K-11)

... that type of mental illness is so serious ... too much pain and suffering but there is no medicine for it ... it is better the person did rather not live at all ... (CAM-M-9)

The participants' viewpoints regarding their understanding of the chronic nature of *ngikerep* demonstrated that the mental illness was irreversible:

... *ngikerep* does not stop ... the person that has it neither gets relief nor recovers ... (FGA-M-2)

The prognosis of *ngimathimathi* was reported to also take a similar illness trajectory to *ngikerep*:

... by the time it is declared as *ngimathimathi* they would have killed animals and made all kinds of sacrifices. They also would have tried the different ways of dealing with it but it persists and overstay without any hope for cure. (CAM-M-9)

In comparison, the prognosis of *ngiwai wai* was described as severe and episodic. For example, a participant explained the nature of illness episodes as follows:

... well, it takes time to understand a *ngiwai wai* ... for the illness situation follows some kind of cycle, getting worse at certain times of the year. Usually it is bad in the dry season ... aah from July ... and gets fairer at the start of the rains in March ... April. When you notice that the patient starts to talk anyhow then know trouble is soon coming. Such is the time for one to do all sorts of funny things ... act restless and even scare others ... but later gets withdrawn and calm again ... that is the *ngiwai wai*. (CTH-M-1)

Others believed that *akiyalolong* was acute and reversible:

... people will say words that show they feel terrible like, "... my heart is burning" ...
 "I feel life is worthless . . .", but somehow they manage to get on with life their lives
 ... (FGA-K-7)

4.3.7. Health-seeking

Disturbances in thoughts and feelings that resulted in *akiyalolong* were considered reversible. The strategies used to deal with *akiyalolong* include providing social and emotional support and engaging individuals in activities that enable them to cope with adversity. For *ngikerep*, *ngimathimathi*, and *ngiwai wai* indigenous healing was sought. However, participants expressed mixed feelings regarding the efficacy of indigenous healing for the treatment of "illness of spirits". Bio-medical care was not sought because it was considered neither a cure nor a suitable therapy for "illness of spirits":

... we don't take people with such illnesses to hospital because we know the illnesses are caused by spirits ... we take them to *emuron* (male traditional healer) ... for situations like that the patient's life is the power of spirits, not anything else ... (FGA-M-2)

... no, we don't, we don't, we don't take to hospital ... once the brain is spoilt and *emuron* cannot help, it is spoilt ... you cannot rely on the hospital ... (CAM-K-14)

The data showing participants' ideas about health-seeking actions for mental illness experienced by adults is presented below.

4.3.7.1. Social and emotional support

Giving social and emotional support to individuals faced with the adversity resulting from *akiyalolong* was described as one of the core aspects of the Karimojong tradition that promotes continuity in society:

... we have always done that as part of our tradition ... if calamity befalls you, say you lose your entire herd to raiders or to epidemics, your relatives and good friends come to your rescue ... you will receive one cow from here ... another from there ... slowly you are helped to start a new herd again ... so you can drink milk, eat meat ... to keep going ... (FGA-K-8)

... ours is a communal life; we feel and care for one another ... take the example of when *manyattas* are maliciously burnt by enemies or by other means ... everyone is called upon ... the men, women and children will do different tasks to build new huts for those in need ... (CAM-M-11)

Another dimension of social and emotional support was to restore emotional wellness when an individual had suspected *akiyalolong* arising from bereavement:

... there are people who tend to get overcome by grief when they lose their dear ones ... the elders are keen to watch their behaviour ... they counsel them as they commiserate ... they leave you when they know you can recover ... (CAF-M-6)

4.3.7.2. Personal coping

Normalisation of illness and self-medication were the two personal coping strategies that people with *akiyalolong* were reported to engage in:

... many terrible things have happened ... at first they would make one to worry a lot ... but the thing is that you are not alone ... as long as you still live then you have to appeal to your inner strength and move on ... (FGA-K-8)

In terms of self-medication, men, women and the youth engaged in sniffing and chewing cured tobacco. This practice was commonly described as *akinaar etaba* (“snuff”). Although, “snuff” was used for different cultural purposes, some of which were intended to create and cement social bonds, the participants explained that its main function was therapeutic:

... snuff refreshes the mind so that you become alert ... it helps to keep your eyes open ... that is our traditional medicine that we have to use whenever we feel low ... (FGA-M-1)

4.3.7.3. Indigenous healing

For most participants, adults afflicted with “illness of spirits” were not cured despite accessing the services of indigenous healers:

... once it is taken that the you have been cursed or attacked by spirits ... nobody will take trouble to make to ... or look elsewhere but the solution will be to try to fix it traditionally with the help of *ngimurok* ... and when the condition gets out of hand you are left on your own ... (CAM-K-14)

... they (“illness of spirits”) are the worst ... there is no cure no matter what is tried ... the patient is taken to *ngimurok* ... they try different things but fail and you are forced to give up ... (FGA-M-4)

Some participants believed the illnesses were curable:

... I can tell you we have local powerful medicines for such illnesses ... we don’t really rely on hospitals ... they cannot treat such problems ... for all these years the government has been giving us nothing ... but we have managed ... (CTH-K-2)

While referring to victims of *akapil* (witchcraft) and *amuronot* (female possessed by ancestor spirits), a participant said:

... for an innocent victim of *akapil* (witchcraft) we divine and treat the person without any difficulty ... but not if you are punished for evil doing ... the same applies to *amuronot* ... that is how she is initiated into the trade of healing ... (CTH-M-1)

In summing up the challenge of lack of cure for “illness of spirits”, a participant said:

... *Lopai* (my friend), by the time you see someone is left to *akirimit* (roam) ... then know that matters are out of hand ... he cannot be helped ... it means his people have tried and failed ... that they have lost the hope that that person will ever be the same again ... he is just useless and waiting for his time to go to his creator. (KI-M-15)

This sub-section has presented the results of the conceptualisation of mental illness in adults. It provided an overview of the lay conceptions of mental illness, and presented detailed description of participants’ views of mental illness with respect to the manifestations, aetiology, impact, prognosis and health-seeking. The next sub-section presents the results of conceptualisation of mental illness in children.

4.4. Conceptualisation of Mental Illness in Children and Health-seeking behaviour

This sub-section presents results of the how participants conceptualised mental illness in children. Despite the general view held by participants that children in Karamoja rarely suffered from mental illness, they described two conditions that presented as mental illness, namely *ngibangibangi* and *akirakara*. As a result, this sub-section describes participants' detailed accounts of the two childhood mental illnesses and the associated notions of manifestation, aetiology, impact, prognosis and health-seeking.

4.4.1. Terminologies of mental illness experienced by children

While the themes of *ngibangibangi* and *akirakara* were described differently, there were significant similarities in terms of the overall manifestation. The participants' perspectives illustrating the conceptualisations of *ngibangibangi* and *akirakara* – typologies of childhood mental illness – are presented below.

4.4.1.1. Ngibangibangi

The local idiom of *ngibangibangi* refers to mental illness in childhood that manifests as inability to think and understand things or express feelings expected in given situations:

... is a situation where a child cannot think ... understand and do things ... cannot concentrate on those things that other children enjoy to do ... such as playing ...
(CAM-M-5)

Because of the inability to think and understand things, the participants explained that the local idioms of *ngibangibangi* and *ebangi ebangi* were simultaneously used to describe afflicted children. In both cases, the idioms were used derogatively:

... *ngibangibangi* ... *ebangi ebangi* is an abuse to mean what one says and the things they do are meaningless ... *ngibangi bangit* ... that is “an idiot” ... (FGA- M-7)

the child will not behave in a proper way, walk and talk well ... you will see such essential things missing ... (CAF-M-6)

In addition, the childhood mental illness of *ngibangibangi* bore some similarities with *ngimathimathi* (adult mental illness):

... it is a common illness ... and in some ways *ngibangibangi* and *ngimathimathi* share similar features because there is nothing to expect of a child who has *ngibangibangi* when it grows ... it becomes foolish and useless ... to me, I would say, *ngimathimathi* seems to start in childhood as *ngibangibangi* or being *ebangaanot* (a fool) ... you don't understand a thing ... (KI-M-19)

Ngibangibangi afflicted children were thought to have impaired minds, and to demonstrate a lack of self-awareness and to engage in senseless behaviour.

4.4.1.2. Akirakara (Kipapa)

Akirakara and *kipapa* (as described by the child participants) are two local idioms that were used to refer to a second typology of childhood mental illness. According to the participants, the word *akirakara* derives its meaning from another term, *akirakar*, which means to faint. In the context of this meaning, children afflicted with *akirakara* frequently fell and lose consciousness:

... *akirakara* means a mental condition that usually attacks children ... the attacks come with a lot of force that a child often falls ... this goes on for a while not until the child faints ... (CAF-M-6)

As noted above, the child participants used the local idiom of *kipapa* instead of *akirakara*:

... she becomes violent and does terrible things ... the same bad things someone with *ngikerep* does ... fights, grabs and throws things ... talks bad words ... she fights ... falls down, gets up and falls several times ... everything stops when she is defeated ... (FGC-M-1)

Regardless of the idiom used, not only was *akirakara/kipapa* believed to be prevalent but was also identified as a childhood specific mental illness:

... *akirakara* ... is a big problem here ... it has become a common problem that these days many children are born having that problem ... it is noticed as soon as they are born ... (FGA-M-1)

However, the adult participants clarified that the child participants' use of the idiom of *kipapa* derived from their understanding that when an afflicted child suffered an attack, it lay powerless and lifeless as if it was "dying":

... you know it is like the child is "dying" ... it *paa* (falls) ... gets up, then *paa* (falls)
... that continues for many times only to stop as the child lies powerless and lifeless
... like someone who is "dying" ... (FGA-M-4)

The participants' view that the experience of *akirakar/kipapa* among children was a childhood mental illness was also based on the recognition that afflicted children behaved strangely, when they suffered attacks:

... you will agree with me that *akirakara* ... makes a child to do strange things ... the nature of its force is so harsh that it makes the child seem wild ... acting so restless as she is constantly thrown down ... and left lifeless ... when it comes back to life, the child is all too confused and worried to ... (FGA-K-11)

... it is nothing but fighting for life ... the thing is that it makes you think that there are spirits disturbing the child ... spirit possession of sorts... (CAF-K-13)

4.4.2. Manifestations of Ngibangibangi and Akirakara

Comparable and cross-cutting features to adult mental illness were identified in the manifestations of *ngibangibangi* and *akirakara/kipapa*. The features were identified as children having cognitive and behavioural disturbances. Thereafter, these were categorised as learning disabilities, speech problems and severe interference with physical functioning. Children with *ngibangibangi* also had sexual behavioural problems. Yet, *akirakara/kipapa* in children manifested in drooling and frothing at the mouth, and urination and defecation.

4.4.2.1. Learning disabilities

Both *ngibangibangi* and *akirakara* were reported to manifest through the experience of learning disabilities. *Ngibangibangi* afflicted children were said to be senseless:

... the child cannot understand anything however much it is taught ... (FGA-M-4)

... *nenipei* ... too senseless and lifeless to live ... like a premature baby ... (CAF-M-8)

Similarly, *akirakara/kipapa* manifested among children who were observed to be dull, slow at learning and experience memory loss. Dullness linked to *akirakara* was recognised especially among older afflicted children:

... is too dull and passive ... child does not easily respond to things because it lacks the ability to interpret situations ... (FGA-M-4)

4.4.2.2. Speech problems

Speech problems were another manifestation of *ngibangibangi* and *akirakara*:

... often they behave as if they are deaf and dumb... (FGA-K-11)

... as a mother, most times you are left confused and worried because the child usually keeps quiet and when she talks, she says so many things some of which are not sensible ... (CAF-K-12)

... a child who has *kipapa* does not talk well ... *nginikamunit ekuwam* (as if possessed by spirits) ... always gapes and leaves the mouth open with saliva running out ... (FGC-M-2)

4.4.2.3. Severe interference with physical functioning

Affected children were described as having deficiencies in functioning related to ability to acquire and exercise motor skills. They could not also do the tasks adequate for their age, including showing difficulties in feeding:

... usually, there are early warnings that a child may be developing *ngibangibangi* ... taking too long to crawl and having difficulties in learning to crawl are indications of it ... the case is more pronounced when the child fails to walk ... (CAF-M-6)

Another female elderly participant and a grandmother said:

... such a child may grow fast and fat but does not move from where it is ... by any chance if it happens to walk, its body movements will not be coordinated ... (CAF-K-12)

... you can tell that a young baby has *akirakara* ... from the way it becomes restless and cries ... unusual crying of very high ... it will also delay to sit, crawl and walk because of falling sick from time to time ... (FGA-K-12)

In linking childhood mental illness to children's lack of physical skills required to complete appropriate developmental tasks, children's views contrasted with those of adults:

... the child always falls and badly hurts herself ... she does not do chores in the household like other children do ... cleaning, fetching water and firewood ... (FGC-M-1)

But the adult participants explained that afflicted children failed to perform tasks because they were unable to think:

... children with those problems ... cannot do the things that would be expected of their age ... they are unable to do tasks given to them because of *nginilutiang* (inability to think) ... (FGA-M-6)

The participants perceived children who were faced with difficulties in feeding as one of the indications of suffering *ngibangibangi*:

... you have to be watchful all the time ... or else anything the child picks ... soil, leaves, dirt and all kinds of things ... even faeces just end up in its mouth ... (FGA-M-6)

4.4.2.4. Sexual behavioural problems

These were described only in reference to *ngibangibangi*. Afflicted children were described as engaging in sexually intrusive behaviour such as fondling and playing with the genitals of other children or engaging in "inappropriate play":

... a few times a child with *ngibangibangi* tries to play with other children ... you get so worried to see that the only things such a child may show interest in is trying to play with the genitals of others ... and as if it enjoys beating other children in case they try resist ... (FGA-K-8)

... it does not want to dress ... as soon as you make it to dress, the child will remove the clothes and throw them away ... at times it behaves in queer ways like it wants to suck at ... of other children ... (CAF-M-7)

4.4.2.5. Drooling and frothing at the mouth

Both children afflicted with *ngibangibangi* and *akirakara* were described as drooling and frothing at the mouth:

... yes, they are so helpless that in most cases saliva pours out of the mouth uncontrolled ... but unlike ... those with *akirakara* will froth at the mouth especially suffer the pain of attack during violent attacks ... (CAF-M-8)

... the attacks come with so much force that however much the child struggles it gets overpowered ... *ajeele* (froth) ... is what you see covering the mouth as her body gets so weak ... (CAF-M-7)

4.4.2.6. Urination and defecation

Children with *akirakara* were reported to urinate and defecate on themselves during attacks:

... the moment the attack comes, the child falls down terribly ... shaking the head and thereafter the rest of the parts of the body ... drains all the energy in her ... until she is left unconscious ... life only comes back after urination or defecation ... it is not the same without an attack ... (FGA-K-7)

... when it comes, she falls badly and bites herself ... you see uncontrollable passing of urine and stool ... before she later wakes up ... (FGC-M-4)

Given the descriptions above, it should be noted that the main feature used to identify *ngibangibangi* among children was inability to understand things. Conversely, *akirakara* was recognised by the violent nature of attacks followed by loss of consciousness.

Next, I present participants' views about the aetiology of the childhood mental illnesses of *ngibangibangi* and *akirakara*.

4.4.3. Aetiology of Ngibangibangi and Akirakara

The aetiology of *ngibangibangi* and *akirakara/kipapa* was described in three categories – biological/physical factors, social/cultural factors and supernatural factors. There were, however, significant similarities with regard to the manner in which biological and supernatural factors were described. The suffering of *ngibangibangi* and *akirakara* will therefore be discussed together.

The social/cultural factors believed to cause mental illness in childhood, largely referred to *ngibangibangi*. However, the suffering of *akirakara* was attributed to one cultural specific aetiology. I will thus present the participants' views about the causation of childhood mental illness in two parts. Firstly, I will present descriptions of biological and supernatural aetiologies of *ngibangibangi* and *akirakara*. Secondly, I will present the social/cultural aetiologies of *ngibangibangi* and *akirakara*.

4.4.3.1. Biological/physical factors

The biological/physical factors that were described were genetic and injuries from physical trauma:

... there are children born like that ... no spirit to live ... the child neither cries nor is it active ... kicking and pulling limbs ... when that happens you can tell there is a problem right away ... (FGA-M-4)

Equally, children with *ngibangibangi* and *akirakara* were thought to acquire them if there was a known history of either of the illnesses in their families:

... once the illness is already there in the family then you can be sure it was passed on to the child who has it by the parent ... (FGA-K-7)

... there are clans where such problems are in blood ... so they persist from one generation to another ... (CAM-M-1)

In contrast, the participants described some children suffering *ngibangibangi* after their mothers had experienced complications during delivery:

... some children get that illness from going through a difficult birth ... the mother struggles so much and may get so tired ... by the time she finally pushes that the child is so weak ... (FGA-K-10)

4.4.3.2. Supernatural factors

The attribution of supernatural factors to the causation of *ngibangibangi* and *akirakara* in children were similar to those for adult mental illness. Despite the similarities, slight variations were observed with regard to particular dynamics of supernatural causation of childhood mental illness. As such, the specific supernatural factors mentioned were *ngilam* (curses), *ngicen/ngawuyonito* (the spirits of dead people or ghosts), *akisub l'thuam* (bewitchment), and *ekinyit* or “bird of bad omen”.

4.4.3.2.1. Ngilam (curses)

As an aetiology of childhood mental illness, *ngilam* (curses) were reported to specifically contribute to the suffering of *ngibangibangi*. It was reported that unlike adults, children's suffering of *ngibangibangi* was a result of the indirect influence of *ngilam* (curses) that had been placed on their parents:

... it is true that *ngilam* (curses) cause *ngibangibangi* in children. But in our culture, a child cannot be cursed ... children are innocent. Children only inherit a family curse. The curse starts with the parents and then that becomes *ngaronon* (for the whole family) ... (FGA-M-1)

... we believe that once a curse is placed on an adult, it follows their blood ... so that will run in the family. For example, once Longole is cursed then the children are cursed as well. That is if someone comes to a home and finds a child with ... they take it that child carries a family curse ... a curse follows the lineage ... (CAM-M-5)

Cursing children was not seen as a common cultural practice as they were presumed to be morally innocent:

... to curse a child is something unheard of ... children are not morally responsible for anything ... and that is why most people take it that they don't usually suffer mental illness ... and if they do, they cannot be blamed for it ... (KI-M-19)

4.4.3.2.2. Ngicen/ngawuyonito (the spirits of dead people or ghosts)

As in the case of *ngilam* (curses), children were seen as indirect victims of ghosts and malevolent spirits. Ghosts and malevolent spirits were described as attacking pregnant women who then passed on the misfortune of suffering illness to their babies:

... *ngicen* ... will attack a pregnant woman as she goes to fetch water but she may not know until she delivers a baby who has *ngibangibangi* ... (FGA-K-12)

... an expectant mother has to be extra careful as she goes to the well to fetch water or to the bush to gather firewood ... it is in such instances that *ngicen* ... can attack her ... and will make the baby ill ... (CAM-K-14)

For *akirakara*, it was believed that malevolent spirits of people killed by the afflicted children's grandfathers sought retribution by attacking the children. And, it was believed that this happened because the dead people had themselves also suffered from the same affliction:

... and do you know? For *akirakara* ... like if the great grandfather killed somebody who had it ... maybe he was falling on fire ... then by mistake say during the raid he killed that person ... that person's spirit comes to his home ... it is brought home by the blood carried on the spear he used to kill the dead person ... we say the spear brought the spirit home ... so it catches one of the grandchildren ... (FGA-M-6)

4.4.3.2.3. Akisub l'thuam (bewitchment)

Similar to the attribution of *ngibangibangi* and *akirakara* to the influence of *ngilam* (curses) and *ngicen/ngawuyonito* (the spirits of dead people or ghosts), afflicted children were also said to be indirect victims of *akisub l'thuam* (bewitchment) and that this occurred in two contexts. First, *akisub l'thuam* (bewitchment) was completed in the context of a pregnant woman being punished for engaging in immoral conduct (bad behaviour). Second, a pregnant woman was a target of *akisub l'thuam* (bewitchment) out of *arakao* (jealousy):

... when that happens, people believe that it is a problem on the part of parents, especially the child's mother ... so usually, people will ask questions regarding her moral conduct ... they suspect that it should be punishment for bad behaviour ... (CAF-M-6)

... *arakao* (jealousy) is a bad thing ... it makes some women to do such terrible things to their co-wives and that certainly affects the baby if the mother happens to be expecting ... (FGA-K-9)

Akirakara was also described as being caused by malicious acts of suspected witches who were believed to directly cast an evil eye on innocent child victims:

... you must keep a watchful eye on your baby otherwise witches will get a chance to harm it ... sometimes you may fail and that is when someone casts an evil eye ... the baby suddenly starts fainting and getting too ill ... and will from then on get attacks ... (CAF-K-12)

The child participants' views were consistent with those of adults regarding how, out of *arakao* (jealousy), witches were believed to cause the suffering of *akirakara* in children. They stated that witches (or people with an evil eye) targeted wealthy and prosperous people. And consequently, the children also became victims:

... there are people who bewitch others because they don't want to see good things ... they hate our parents and hate us the children and that is why some children get *kipapa* ... (FGC-M-3)

4.4.3.3. Social and cultural factors

The suffering of mental illness among children was attributed to the influence of specific social/cultural factors. These included the failure to perform cultural rituals, transgression of taboos such as committing *elomanu* (adultery) and teenage marriage. These factors, however, were largely associated with the causation of *ngibangibangi*. In contrast, the causation of *akirakara* was attributed to a specific aetiology called *ekinyit*; "a bird of bad omen":

... failure to observe cultural rituals in relation to a new born, for example, in our tradition, after birth a boy child must not be brought out of the house not until after four days ... and for a girl it takes three days ... sometimes this is not followed ... that is how children become ill ... (FGA-M-5)

Committing *elomanu* (adultery) by parents was used as a cultural explanation for the onset of *ngibangibangi* in children:

... that [*ngibangibangi*] is one problem we expect of children of spouses who are *elomana* (adulterous). This also comes with all sorts of problems in one's marriage life ... (CAF-K-13)

Teenage marriage was also a factor in *ngibangibangi*:

... some parents force their young daughters to marry ... you find a child as young as 10 years is allocated to an old man because her parents have greed for cows ... in instances like that you find that she produces a baby with that problem ... (CAM-K-14)

In the case of *akirakara* that was suspected to originate from the cultural specific aetiology of *ekinyit* ("a bird of bad omen"), afflicted infants were said to experience persistent convulsions. These happened when the *ekinyit* soared several times in the skies above the family house as the baby slept:

... if a child convulses nonstop that is seen as an attack ... we say *ekinyit* ... passed many times over the house while the baby was asleep ... sometimes, the baby also gets rash all over its body and may even die ... (FGA-M-5)

Next, I present the impact of suffering *ngibangibangi* and *akirakara* during childhood among the Karimojong.

4.4.4. Impact of Ngibangibangi and Akirakara

The impact of suffering *ngibangibangi* and *akirakara* in childhood was reflected in the different negative aspects of life that confronted afflicted children and their families.

Regardless of the nature of childhood mental illness, the negative aspects were considered to significantly impact child development with similar outcomes. These were disability, social dysfunction and poor physical health, including stigma of afflicted children and their families.

4.4.4.1. Disability

Both *ngibangibangi* and *akirakara* afflicted children were reported to be disabled because they failed to learn things they were taught:

... the thing is that, that child does not pick anything, not even the meaning of a simple thing like dressing ... for example, you teach it how to dress and demonstrate by helping the child to dress ... immediately, the child throws away the ... and remains naked ... suggesting to you that it lacks the ability to learn ... (FGA-K-10)

It was reported that children with *ngibangibangi* and those with *akirakara* failed to access formal schooling due to being mentally disabled:

... you may know that not many children attend school here . . . The challenge is bigger with children who are disabled because of *ngibangibangi* and *akirakara* ... they cannot make it to school and if they did, how will they learn if they cannot understand things? (CAM-K-16)

4.4.4.2. Social dysfunction

The social dysfunction of children with *ngibangibangi* and those with *akirakara* was seen as being linked to their exclusion from participation in household chores, and their failure to create sustainable relationships with other children. Adult participants stated that afflicted children were exempted from doing household chores because they were prone to fatal accidents:

... you cannot be sure when the attack comes ... often it happens in situations where it is difficult to do anything ... fire ... water ... because of fear you are forced to discourage the child from doing household chores ... many meet their death by falling in the fire or drowning. (FGA-K-10)

A distinction was made between *ngibangibangi* afflicted children and those with *akirakara*:

... you see the child feels so agitated for any little thing that happens to it ... sometimes it is as if it enjoys beating other children ... not attentive whatsoever ... (CAF-M-8)

For children with *akirakara*, the challenges were twofold: fear of other children that *akirakara* afflicted children would commit acts of violence against them:

... they cannot be your friends when they like to fight and beat you ... you go away they chase and throw stones at you ... (FGC-M-1)

4.4.4.3. Poor physical health

Participants thought that besides suffering *ngibangibangi* or *akirakara*, afflicted children also experienced poor physical health and a high risk of mortality:

... from birth the child is too weak and lifeless to be a normal person ... it is bad luck ... that child's future will be difficult with many illness coming from time to time ... until you may be forced to leave everything to *aku*j (God) ... (FGA-K-11)

... *akirakara* causes a lot of other difficulties for the children ... numerous scars from healing wounds and also fresh ones especially facial injuries ... you cannot say that the child shows any sign of well-being ... life is generally bad ... (FGA-K-11)

A caregiver of one child that had *akirakara* shared her experience of the child's illness:

... the whole experience is complicated and miserable ... she may be active on some days without any sign of attack ... but still she will complain of pains in her body ... (CAF-M-7)

In describing the high risk of mortality:

... for those cases death is inevitable ... a lot of times, children born like that die ... (FGA-M-4)

... there are a lot of difficulties that come their way ... some cannot tell you when they are sick, you only guess that there may be a problem when the child refuses to eat ... things are even worse for those with *akirakara* ... they may run away from home and end up ... (FGA-M-4)

4.4.4.4. Stigma

As in the case of adults, participants described negative societal attitudes towards children afflicted with mental illness and their families. This manifested in the form of societal blame of parents and social exclusion, particularly parents of children with *akirakara*. Childhood mental illness was considered a familial misfortune and a consequence of immoral conduct by parents:

... *ngibangibangi* is one of those most unfortunate things that can ever happen to your child ... it is seen as a misfortune in the family and *akisitakin* (blame) is placed on you ... our people look at it that way ... (CAF-K-12)

... it means there is something not right in the family ... this may have taken some time to happen but still it does come up ... the illness ... will attack one of the children ... it comes to haunt them ... (FGA-M-3)

Compared with *ngibangibangi*, shame was inherent in familial experience of *akirakara*:

... how do you avoid the feeling of shame when other people think of you as evil? To them the child's suffering is only seen as just a reminder of ... (CAM-M-3)

Consequently, in an attempt to prevent situations that would result in experiencing shame, it was reported that some families of children with *ngibangibangi* hid them from other people:

... some people with bad hearts might harm them ... but I think that the fear is more than that ... shame makes parents to hide children with *ngibangibangi* inside their houses ... they decide to restrain them from going out to wander about ... (CAM-M-2)

Similarly, the mothers of infants with *akirakara* were described as keeping their children away from the eyes of the public in order to avoid shame:

... mothers of infants with *akirakara* hide them from outsiders under the guise of preventing the evil eye ... to hide them from the attention of outsiders in order to avoid ... (CAF-M-8)

In addition to not attending school, children with *akirakara* were not allowed to attend public activities and events such as prayers:

... they cause a lot of problems ... you cannot risk taking them along with you to public events or gatherings like say when you go to church for prayers ... they will mess up things and become a nuisance to people ... (CAF-K-12)

There was also a fear that the illness was contagious:

... yeah, there seems to be the fear that if children with *akirakara* ... are allowed to play, in the long run other children may get the illness through close contact with them ... (FGA-M-2)

It was also believed that parents of afflicted children might engage in actions harmful to other children:

... there is that feeling that *arakao* (jealousy) can drive parents of children with the illness to put other children's lives in danger ... the situation is that bad for them ... they find themselves subjected to loneliness ... (FGA-M-6)

Families were also excluded with the refusal by other people to marry adults from families with afflicted children:

... children with that illness rarely survive ... What is more disturbing though is that people fear that the entire family carries the illness in their blood. For example, people will refuse to marry from the family if they know there is that illness ... (FGA-K-11)

4.4.5. Prognosis of Ngibangibangi and Akirakara

The participants expressed mixed reactions towards the prognosis of mental illness experienced by children. Some participants described both *ngibangibangi* and *akirakara* as severe and chronic illnesses. Others believed *akirakara* was severe but curable:

... whatever you try, *ngibangibangi* cannot be cured ... children who get it usually die because of that illness ... (FGA-M-5)

... it is a complicated illness ... its nature has defeated many people to understand ... from my experience I have never seen a child afflicted with *ngibangibangi* get cured ... (CAF-M-8)

... there is fear that if a child with *ngibangibangi* grows up it can become a useless person like someone with *ngimathimathi*... (KI-M-19)

For those participants who thought *akirakara* was severe and chronic:

... for *akirakara* you expect similar results like *ngibangibangi*, a child cannot get cured ... you only try to manage their effects with the help of ... if there is luck, a child gets well and lives normally but that will be for a short time before it comes back ... it will be on-and-off ... there is nothing like complete cure... (FGA-M-2)

In contrast, the understanding that, despite being a severe childhood mental illness, *akirakara* could be cured was linked to its cultural specific aetiology:

... it can be stopped if it is noticed at a very early age ... rituals will be performed and 'the spear brought the spirit home' will be destroyed to free the child ... (CAM-M-1)

4.4.6. Health-seeking

With respect to health-seeking, the participants outlined the types of treatment sought for the care of childhood mental illness as indigenous healing and bio-medical care. They also stated that while indigenous healing was sought for the management of both *ngibangibangi* and *akirakara*, bio-medical care was exclusively sought for the treatment of *akirakara*.

4.4.6.1. Indigenous healing

With regard to the use of the services of indigenous care providers to treat *akirakara*, participants expressed mixed reactions about its efficacy. For those participants who thought that *akirakara* was curable, they explained that the illness could be effectively managed if it was detected early:

... we have old wise people who deal with *akirakara* quite well ... provided the signs of the illness are established early enough ... it is something those people do to help infants with such a problem ... (CAM-K-14)

... it is possible to cure the illness once the signs of attack such as a baby getting repeated convulsions show when the baby is a few weeks old ... (CAF-K-12)

... there is medicine for that illness ... we able to treat it ourselves. I can tell you there is nothing too difficult to manage ... (CTH-K-2)

4.4.6.2. Bio-medical care

As mentioned above, apart from seeking help from indigenous healers, bio-medical care was also sought for children with *akirakara* but this was also seen as to be not successful:

... the people living near town [Moroto] try to take their children for treatment at the hospital but they still fail to cure ... they are forced to come back home after being frustrated ... (FGA-M-4)

... they take them to *edakitar* (hospital) ... but when they come back the children still fall down, hurt themselves, run around ... (FGC-M-3)

In the view of some participants, the utilisation of bio-medical care by the community was made difficult because of poor services:

... while our people may have other reasons for not seeking care for children with those difficulties from ... hospital, I think that the major issue is that the facility itself is limping ... it is in a very poor state ... the hospital is just in name ... the buildings are the only ones ... but no services ... the staff are instead the ones who are mental patients ... they sleep in the houses that are supposed to be laboratories for patients ... (KI-M-13)

... many times you will take the child to hospital but get no help ... instead, you will be told there are no drugs for that ... and in case of luck, you will receive drugs but they say, "... this is just for control . . ." (FGA-M-4)

This sub-section has presented the results of conceptualisations of mental illness in children: *ngibangibangi* and *akirakara*. It has also described participants' perspectives of the manifestation, aetiology, impact and prognosis of the illnesses, including health-seeking responses for their treatment. The following sub-section presents results of conceptualisations of mental illness experienced by both adults and children.

4.5. Conceptualisation of Mental Illness in both Adults and Children

4.5.1. Introduction

This sub-section presents the results of conceptualisations of mental illness in both adults and children. It also describes the reported manifestation, aetiology, impact and prognosis of the mental illness.

4.5.2. Terminologies of mental illness in both adults and children

Mental illness experienced by both adults and children was identified as *akibwal*.

4.5.2.1. Akibwal

Participants used the local idiom of *akibwal* to refer to the expression of negative emotions with a particular emphasis on shock and anxiety. They reported that the experience of such feelings resulted from the exposure of adults and children to terrifying events such as witnessing violent arrests, torture and killing of people:

... *akibwal* is how we call that feeling of shock in one's heart ... for example, here live we under constant fear ... should you hear someone complain of *akibwalayong*, it means, they are expressing shock because of a terrible incident ... (FGA-M-1)

... one time the soldiers cordoned off our village ... they told us it would be a peaceful search ... but as it turned out they tortured men and harassed boys ... although they did nothing to women, I tell you I had *kibwal* (my heart fell) ... I always get that same feeling whenever I think about it ... (CAF-M-6)

4.5.3. Manifestations of Akibwal

Akibwal was described as manifesting through a combination of affective and behavioural symptoms. The expression of the symptoms of *akibwal* by adults was also seen as differing slightly from the way it was known to present in children. In the case of adults, *akibwal* largely manifested through the expression of negative affective symptoms, while for children, *akibwal* mainly manifested through behavioural symptoms.

4.5.3.1. Affective symptoms

Affective symptoms of *akibwal* were described as feelings of anxiety coupled with wakefulness:

... life is difficult ... as the sun sets you increasingly get uncertain of what to expect ... you keep awake in anticipation that the worst is coming ... the fear is so deep that your heart goes beating on hearing any noise ... (FGA-K-7)

... you experience shock all the time ... that goes on day in and day out ... you get so apprehensive ... you keep watching everything all the time ... (CAM-K-15)

For the children, two interrelated scenarios were described by the participants to illustrate the affective symptoms of suffering *akibwal*. In the first scenario:

... when children get *akibwal*, they tend to be absent minded ... they have problems of concentrating on the things they do ... (CAF-M-8)

In the second scenario:

... you can notice in a child when it acts like *aleerekongu* (stares without blinking) at things and gets easily frightened ... (CAM-M-2)

4.5.3.2. Behavioural symptoms

The behavioural symptoms of *akibwal* were persistent crying, running and hiding from people:

... children who have such a bad experience tend to cry a lot ... you will face a serious predicament because of *aresiyaar*, which means a baby will cry persistently without any apparent cause ... (CAF-M-8)

... it is also common for children with that problem ... to run and hide on seeing anybody ... that happens whenever they see strangers. You know when the soldiers conduct their operations they first capture the children and beat them so that they reveal if their families had guns. Secondly, they sometimes dress as civilians then arrest and torture people. The children have been through all that and that is why they run away ... (CAF-K-12)

4.5.4. Aetiology of Akibwal

The aetiology of *akibwal* was attributed to psychosocial factors linked to actions by cattle raiders and government soldiers: (a) insecurity and lawlessness, (b) violent arrests, torture and detention, (c) witnessing killings, (d) shooting of heavy guns and movement of military hardware, and (e) rape. Below, I present the participants' accounts of the perceived contribution of each of these factors to the causation of *akibwal* among adults and children.

4.5.4.1. Insecurity and increased lawlessness

All the participants attributed the suffering of *akibwal* by both adults and children to their experience of insecurity and increased lawlessness caused by cattle raids:

... we have *ngakiro ka' arem* (a lot of insecurity) from raiders ... everyday we suffer fresh wounds ... they loot cows ... order everyone out of the manyattas, then torch them ... they kill ... lucky survivors are left maimed ... these are the scars that you see ... (CAM-M-10)

... there are enemies from all corners ... Turkana, Pokot from Kenya ... Toposa from Sudan, some from Ethiopia ... they take herds and abduct people ... you think of the missing children and the horrible acts ... it is too much to bear ... we are a trapped community ... (FGA-K-12)

The government's failure to protect the Karimojong despite increasing insecurity was seen as causative:

... *egurigur alotoma* (violence is too much) ... we have never faced this kind of situation before ... that you lose everything ... cows, your children ... we have been neglected by government and left at the mercy of raiders ... it is really disturbing ... (CAM-M-10)

4.5.4.2. Violent arrests, detention and torture

The attribution of suffering *akibwal* to violent arrests, detention and torture originated from the military-led forceful disarmament in Karamoja.³² Within this context, the participants

³² These were described as examples of inhuman methods used by the military during the forceful disarmament in order to extort information about illegal ownership of guns and recovery from the local population in Karamoja.

stated that because of the forceful removal of guns, the hitherto absent government presented itself as another enemy of the people:

... it is only until recently that we started to experience the government through the disarmament ... at first we embraced the programme with optimism thinking that it would stamp out anarchy and bring peace ... but instead of offering security they (soldiers) have turned into our tormentors ... violence and fear have intensified because of excessive use of force and widespread abuse of human rights as they also loot our cows ... (KI-M-19)

The participants also explained that initially the people had embraced the disarmament because not only had the programme been seen to be participatory but also voluntary:

... as mothers, women and elders, we vigorously participated in the first disarmament because it was voluntary ... we queued in front of the president to hand over the guns on the promise of peace but we were totally let down ... (FGA-K-12)

... most of us, and particularly women were for peace; we did whatever it took to hand in the guns ... and for a Karimojong woman to get a gun from that warrior, ooh, the amount of quarrelling, the amount of bashing, abuses she has gone through ... and for her to convince including sanctions, you know, sanctioning the men until they give in, until they give the gun. The women did all that thinking that this government was right ... that it was worth being trusted, that if you give in guns they will come and protect you. That was never to be ... the raiders came to those families that had given in their guns and the suffering started all over ... they took cows, killed people ... (FGA-M-1)

In their discussions attributing the suffering *akibwal* to violent arrests, detention and torture, the maltreatment of men by the military was a common theme. The process was said to involve the encircling of entire villages and indiscriminate arrest of suspected rustlers by the military:

... whenever there is a cordon and search operation all the young men are brutally arrested ... they are treated as dangerous criminals because in the eyes of the soldiers every Karimojong man is a warrior and a suspected rustler ... they then tie the suspects on those war vehicles [Armoured Personnel Carriers – APCs] and drive them

to the barracks in broad day light under the hot sun for everyone to see ... many families are left in shock and those released continuously live under the fear of being rearrested by soldiers ... (CAM-M-11)

The experience of *akibwal* was also described as being caused by the use of harsh methods by the military as a way to obtain information about gun ownership from the local people:

The soldiers tie the suspects' legs up in the tree in order to suspend the body with head facing down. They then hit the muscles and veins between the anus and the testicles ... we compare it to *ticktia pturus* (castration) ... (FGA-M-3)

The suspects' hands are tied up in the tree and they are made to suspend above the ground. Their heads are covered with polythene bags that make them to suffocate while they are being beaten ... as this goes on, the victims defecate on themselves helplessly and only to let "free" when they become unconscious. When they regain full consciousness, they are not given water so that they wash themselves. And, in order to shame them further the soldiers force the victims' wives to come and watch how the once feared and brave Karimojong warriors are actually nothing but cowards who defecate on themselves. They mock their victims by telling them, "If you were real and brave men why did you defecate on yourselves?" (FGA-M-1)

For women, suffering *akibwal* was seen as a consequence of them witnessing the violent arrests of their husbands and sons in addition to themselves being beaten by the soldiers:

... we suffer a lot at the hands of soldiers ... they arrest our husbands and sons, chain them and take them away ... then they *ekidich* (hit you) ... *ekidich* (hit you) as they force us to mention where the guns are hidden ... if they don't get any gun in the Manyatta they will beat you and leave you for dead ... (FGA-M-5)

4.5.4.3. Witnessing killings

The cause of suffering *akibwal* for children was also seen as a result of witnessing killings:

... that problem is common given our difficulties ... but in my view I think that it is too much for our children. They witness as their parents are killed in their presence ... other people are also killed during raids when they are seeing. In the process, the very

young also injured. Having watched such horrible things their minds never clear ...
(CAM-M-9)

I was herding goats and sheep with my uncle when the enemies struck. They ordered us to lie down but my uncle tried to run ... then he was shot. They took all the animals and left me lying and trembling helplessly on the ground ... I was rescued and taken home. Later, I came to stay in this village where you have found me but I cannot forget how my uncle died. (CMC-K-7)

4.5.4.4. Shooting of heavy guns and movement of military hardware

These factors were believed to cause *akibwal* because both adults and children lived under fear of being shot:

... unpredictable gun firing has often made us to worry ... all of a sudden there are bullets being fired in every direction ... making people get afraid of getting shot ... even just the sound of gun shots alone makes people run for their lives ... (CAM-M-5)

4.5.4.5. Rape

In addition to the role of factors described above, women and girls were vulnerable to affliction with *akibwal* because of the experience of rape. The rape of women and girls was reported to be perpetuated by both enemy raiders and the military:

... *aremu* is the source of all evil ... they would take everything but at least save us the shame of being raped ... no man is willing to marry a girl they know was raped ... imagine carrying the double burden of guilt and the fear of being infected with *lodiim* (HIV/AIDS) ... (FGA-M-5)

... they use the excuse of searching for guns to put our homes under siege in order for them to commit the evil of *atikonor* (rape) ... in the process some of us the women and girls are injured or even killed ... (CAF-K-13)

4.5.5. Impact of Akibwal

The impact of suffering *akibwal* by both adults and children presented in two ways – violence and anxiety. Adults were also described as being prone to suicide. The participants'

explanations of the nature of these impacts on the lives of afflicted adults and children are presented below.

4.5.5.1. Violence

Both adults and children afflicted with *akibwal* were known to engage in acts of violence. However, the nature of reported acts of violence had different dimensions:

We women are even distressed further ... the men are now a problem to us ... we have to endure beatings, harassment and verbal abuses by our husbands ... you find that again that warrior [husband] you took the gun from has lost a brother, has lost cows ... always keeps in hiding to evade arrest ... the little time while he at home he turns all the anger and frustration on you.... He starts quarrelling, “You woman, who do you think you are ... where is the gun, where is your father ... whom you gave my gun? Get out from here ...” And before you know it will be all chaos ... that is the kind of life we are talking about ... (FGA-K-12)

... it is hard to explain what exactly happens ... but there are times you find that you doing things that are not good to your husband and children ... you start quarrelling and fighting among yourselves over small matters ... I think that it is as a result of the so many difficulties we face ... (CAF-M-6)

... some children feel angry and bitter because of the bad things they see everyday ... they beat other children at the slightest provocation ... (CAM-M-9)

For the children, the expression of feelings of anxiety due to *akibwal* manifested as sleep problems and having nightmares:

... the effect of cordon and search is devastating on the side of children ... usually the operations start in the wee hours of the morning and by the time children wake up the whole atmosphere is tensed. This may last several hours until dusk ... at night they will not sleep fearing a repeat of what they saw during the day ... (FGA-K-12)

... I always have bad dreams at night. I see soldiers shooting and killing people ... during the dream I feel I that my nose is blocked so I cannot breathe ... I cry so loud but nobody comes to help me ... (CFC-M-3)

4.5.5.2. Suicide

The participants stated that as in *akiyalolong*, some adults with *akibwal* decided to commit suicide as a means of escaping brutality and torture by the military:

Because of the fear of torture, every time the soldiers do operations there are people who decide to kill themselves or run and are shot rather than wait to be brutally dragged to detention in the military barracks and face untold abuse. We can call it a form of suicide that has also taken many lives, besides other forms of death. (KI-M-6)

4.5.6. Prognosis of Akibwal

The prognosis of *akibwal* was thought to be similar to that of *akiyalolong* and thus described as acute but reversible as the participants' thoughts show below:

... yes, we face numerous difficulties and the things that happen to us bring great fear and sometimes there is much panic because you anticipate the worst to come but pain caused by all that happens, comes and goes ... However, the worst memories live on ... (FGA-M-5)

... usually, victims of torture and rape will immediately have so many bad thoughts and feelings that even force them even to hate themselves but will gradually be reversed ... (CAF-K-12)

This sub-section has presented the results of the conceptualisations of mental illness in both adults and children, and described the reported manifestation, aetiology, impact and prognosis of *akibwal*. In the next chapter, I discuss the results.

Chapter Five

Discussion

5.1. Introduction

In this thesis, I examined lay explanatory models (EMs) of mental illness and health-seeking in the context of a humanitarian crisis (or development crisis) in Karamoja, north-eastern Uganda. I also examined what informs lay EMs of mental illness and the decisions to (or not to) seek care. I hypothesised that while culture shapes lay EMs of mental illness, these are also shaped by contextual factors such as poverty, violence and marginalisation. I also hypothesised that a clear grasp of context is vital for a better understanding of how lay EMs and related behaviours are informed by culture (Helman, 1994; Kleinman, 1980). The central argument of this thesis is that lay EMs of mental illness are shaped not only by culture, but also by context. In this chapter, I discuss the themes that emerged from the data. First, I will briefly outline the context. Then, I discuss the results, and specifically, I examine lay EMs of mental illness in Karamoja.

5.2. Karamoja: a context of humanitarian crisis

In this section, I briefly describe the context. The contextual issues that I will discuss are informed by an archival review which I conducted to track the history of Karamoja. As a result, I describe how historical, political, and social dynamics shape everyday life in Karamoja. Specifically, I locate the reality of the Karimojong in the context that creates it and show how they have been constructed and represented in relation to the rest of Uganda.

From 1911, when Karamoja came under British rule, archival accounts of the history of the people reveal experiences of active political marginalisation, economic neglect, and cultural isolation by the state. Since then, Karamoja remains the least developed area in Uganda due to armed violent conflict, persistent insecurity, extreme poverty, chronic famine, poor infrastructure, and lack of social services (Krätli, 2010; Office for the Coordination of Humanitarian Affairs [OCHA], 2011). The people have adopted a pragmatic system of land use, herding livestock and growing food crops. Due to erratic and poor distribution of rainfall patterns, crop farming provides the least viable means for subsistence in Karamoja. For instance, they will sow crops up to five times in one season but only realise a modest harvest. From the 1920s, agriculture has been a secondary activity to herding (Barber, 1962; Gray,

Akol, & Sundal, 2007). There is a constant risk of starvation, and in order to avert famine, the Karimojong have relied on food aid since 1964 (OCHA, 2011).

Although pastoralism considerably contributes to food security and maintenance of social relations, it is also the source of crisis: armed violent conflict, chronic famine and suffering. For instance, cattle raids-related violence is one of the leading causes of male mortality (Gray, 2000; Mkutu, 2010). Armed violence has been part of life for generations in Karamoja, and the region is volatile due to firearms trade and trafficking along the long and porous borders with South Sudan and Kenya (Knighton, 2010). In this context, the lives of the Karimojong have been constructed and understood almost exclusively through discourses of conflict, insecurity and famine (Krätli, 2010).

The case of chronic famine in Karamoja, for example, can be traced from the state's political economy that has since colonialism sought to undermine and destroy the pastoralist economy by forcible acquisition of land (Mamdani, 1982). More critically, this question can be further addressed from the perspective of human rights or entitlements (Sen, 1999). Human rights – entitlements – include freedom by citizens to own and have command over goods, particularly food. This is realised when the state fulfils its duty to citizens by protecting their endowments that include productive resources, production possibilities and their use, and exchange conditions (Sen, 1999). From the viewpoint of the political economy of famine, the loss of these entitlements leads to the lack of access to food by citizens and their eventual vulnerability to starvation. So, one indication that the state has poor political relations with the people is from their experience of famine. Famine is preventable if the state has the political will to address those conditions that destroy people's endowments and shrink their capacities to have access to food, such as prevalent poverty, ill health, and poor distribution of food in the economy (Sen, 1999). I thus argue that factors like severe droughts, livestock diseases, and low food production may accelerate people's vulnerability to starvation, but are not the real causes of famine in Karamoja. Famine is instead a result of the long term active political marginalisation, economic neglect, and cultural isolation of the Karimojong.

With regard to intractable conflict and insecurity, the Uganda government's response to address these issues has been largely ineffective. Interventions such as disarmament have not markedly contributed to ensuring security. Conversely, disarmament has also been associated

with gross human rights abuses. For instance, helicopter gunships have been used to bombard the population arbitrarily. This has resulted in huge loss of life, widespread displacements and destruction of livelihoods, including the seizure of livestock (Bevan, 2008; Stites & Akabwai, 2010). These experiences, in turn, have been linked to increases in psychological trauma and suffering among the population (Gray, 2010).

Furthermore, national politics tends to contribute to cycles of violence by manipulation of pastoralists against themselves and other communities. For instance, until 2007, the Karimojong raided and caused immense destruction of livelihoods among their Acholi neighbours to the west (RoU, 2007) as the government watched without offering solutions, especially protection to the Acholi. Instead of protecting the Acholi and disarming the Karimojong, the latter were left to cause chaos in the hope that this would weaken political opposition by the former, especially through the LRA rebellion (Knighton, 2003; Närman, 2003). Within Karamoja, there is also evidence of imbalances in disarmament. In 2005, for instance, the disarmed Jie group in Kotido was left exposed and vulnerable to the firepower of their fully armed Matheniko neighbours from south Karamoja (Knighton, 2010). Consequently, the government's sporadic disarmament drive was not only regarded as a "source of uncertainty in an uncertain environment" (Gray, 2000, p. 413), but also as a betrayal for those Karimojong who volunteered to disarm. Thus, uneven disarmament often fails to achieve the long term effect of disarming the Karimojong, and in turn fuels their hostility towards the government (Gray, 2000). The interaction of all these factors has led to what has been termed as a humanitarian crisis (WHO, 2007a) or development crisis (OCHA, 2011).

In this context, simply understanding lay EMs of mental illness as cultural artefacts might be utterly misleading because these are shaped by both culture and context. By context, I mean the historical, political, economic, social, and ecological conditions in which people live (Helman, 1994). These conditions, like culture, are constantly evolving. Being that they are products of culture and context, therefore, EMs too tend to shift meaning over time (Jenkins, 2018; Nichter, 2010). Consequently, EMs must be understood within the specific culture and context that people construct them to deal with specific illness episodes (cf. Helman, 1984; Kleinman, 1980). I work with this perspective in my discussion of lay EMs of mental illness that follows.

5.3. Lay Explanatory Models (EMs) of mental illness

In current global mental health debates, the themes of taking cultural issues seriously and sensitivity to local contexts predominate (Kirmayer, 2018; Kirmayer & Pedersen, 2014; Kirmayer & Swartz, 2014; Patel, 2014a; 2014b). Specifically, there is an emphasis on how embracing the knowledge of lay people's EMs of mental illness can inform actions that target them. While nomadic pastoralists are among the most marginalised and poorest people in the world, the question of how they understand mental illness is largely absent from the literature. In what follows, I address this issue. The discussion is structured using Kleinman's formulation of EMs. It has five major components that include notions of the nature, name, aetiology (cause), expected course, and desired treatment of an illness (Kleinman, 1980). But for ease of discussion, I am collapsing nature and name into one sub-section (four main sub-sections). First, I examine Karimojong cultural concepts of mental illness. I then discuss ideas about causation of mental illness. Thereafter, I examine local views about the course and effects of mental illness. Lastly, I discuss treatment of mental illness.

5.3.1. Karimojong cultural concepts of mental illness

In this sub-section, I discuss the Karimojong cultural concepts of mental illness in relation to the psychiatric constructs of psychosis, depression, psychological trauma, epilepsy, and intellectual disability.

Kleinman argues that illness concepts are essential features of EMs, which are used by all cultures to describe distress. Specifically, the concepts reveal the meaning and severity of symptoms, and the psychosocial processes that each culture attributes to distress (Kleinman, 1980). Some have criticised the formulation as being too laborious to use in clinical practice (Bhui & Bhugra, 2002). In addition, failure to do appropriate language translation and a lack of awareness of possible interviewer bias may limit successful use of the EMs framework in research practice (Kirmayer & Bhugra, 2009). However, research has shown that the framework is easy to apply and has utility in examining health beliefs in many cultures, particularly in Africa. Specifically, it has been helpful in eliciting local illness concepts, which are used to interpret and classify psychological distress in different African cultures (Abbo et al., 2008; Kpobi & Swartz, 2018; Lund & Swartz, 1998; Swartz, 1998; Patel, 1995). The Karimojong cultural concepts of mental illness that I documented in my research appear to illustrate these functions, as elaborated below.

5.3.1.1. Psychosis-like cultural syndromes

In psychiatry, psychosis is defined by the experience of delusions, hallucinations, disturbed emotions, and disruptive behaviours (APA, 2013). In Karamoja, the emic concept of psychosis closely resembled but did not neatly map onto its psychiatric definition. *Edeke ka ekuwam* (“illness of spirits”) was the most commonly used idiom for mental illness. But the idiom was used to describe different cultural syndromes. Three of these, namely *ngikerep*, *ngimathimathi*, and *ngiwai wai* closely resembled psychosis, and were thought to afflict only adults. While they were separately named, they shared symptom overlaps such as abnormal thinking, violence, talking nonsense, and neglected self-care. And these experiences and behaviours were associated with impaired psychosocial functioning and violation of cultural norms. This is consistent with cultural understandings of psychosis reported in Africa (Shibre et al., 2010; Ventevogel et al., 2013).

Amongst the Borana pastoralists in southern Ethiopia severe mental illness was understood in a similar way to that of the Karimojong. It was described as *marata* and characterised as an illness that affected only adults. People with *marata* also engaged in violent and aggressive behaviours such as restlessness, roaming and burning houses. These actions were also recognised as forms of behaviours that transgressed cultural norms and resulted in strained social relations (Shibre et al., 2010). The Luo people in Yei (South Sudan) used the local syndrome of *mamali* (“disturbed mind”) to refer to psychosis and described acute psychosis as *ngengere*, while those in Kwajena (South Sudan) named psychosis as *moul*. The Congolese in Butembo (DRC) identified psychosis as *erisire* or *erisire ry'emumu*, and Burudians in Kibuye described psychosis as *ibisazi* (Ventevogel et al., 2013). However, in all the four settings psychosis was recognised as presenting with similar severe behavioural problems. It was particularly linked to interpersonal violence, walking aimlessly or naked, collecting rubbish and talking nonsense, eating dirt, and bad hygiene (Ventevogel et al., 2013).

However, the local and psychiatric concepts of psychosis also differed. Contrary to what psychiatry tends to see as a discrete disease, psychosis was categorised by the Karimojong into three distinct subtypes. And these were differentiated as exemplified by their culture-specific meanings and associated forms of cognitive dysfunction. This indicates that psychosis was understood as a complex and multilayered illness by the Karimojong. This

understanding seems to lend support to the framers of both the DSM and ICD who caution against treating psychiatric categories as entirely discrete entities. It also augments the evidence that although mental illness is a global public health problem, it is flawed to classify and describe its experience in other cultures in terms of DSM/ICD psychiatric nosology. This is because the nosology often lacks validity and makes little sense among local people living in culturally diverse and resource-poor settings (Becker & Kleinman, 2014; Patel, 2014b; Summerfield, 2008). Thus, current results add to the data which call into question the cross-cultural applicability of psychiatric diagnoses. They also support the view that psychiatric diagnoses require elaboration and validation using local understandings and concepts.

It has been argued that there is a need to frame mental illnesses as discrete categories because this can promote research and treatment for a number of mental illnesses (cf. Good, 1997; Saint & Whilte, 2010). But the problem with this thinking is that it favours bio-medical reductionism; the tendency to prioritise the biological basis of mental illness while ignoring its social and cultural roots (Boyle, 2013; Kirmayer & Gomez-Carrillo, 2018; Patel, 2014b). Thus, it is too narrow and perhaps even essentialist. In the literature, it is consistently shown that while mental illnesses are determined by complex interactions of psychosocial and biological factors, a large proportion of them are equally socially and culturally constructed experiences. That is, they lack a clear material reality, but are produced, categorised, and legitimised by society. So their meanings can only be known by examining the cultural and social contexts in which they are embedded (Becker & Kleinman, 2014; Kirmayer, 2018; Kirmayer & Swartz, 2014; Lund et al., 2018).

The Karimojong concept of psychosis is also consistent with what has been found among the Ganda people of south-central Uganda (Teuton et al., 2007; Orley, 1970). The Ganda used diverse local concepts to describe distinct forms of psychosis. They used the term *eddalu* to name the experience of severe psychosis while its milder forms were referred to as *akazole* and *kalogojo* respectively. They also described *kutabuka mutwe* as the mental condition of having “disorganised” head. Similar observations about the classification and interpretation of psychosis have been made among the Basoga (Abbo et al., 2008). The Basoga described psychosis as *eddalu* and *ilalu* and its milder form as *kazoole* (mania). *Kazoole* was also described as an illness with intervals of normality and less serious than *eddalu* (psychosis). The Basoga description of the episodic nature of *kazoole* (mania) is related to the Karimojong

conception of *ngiwai wai*. The Karimojong did not only think *ngiwai wai* was episodic but, in addition, also described the behaviour of people with this type of psychosis as being controlled by a knob that was turned on and then off.

These data also provide insights about lay ideas of psychosis from a different cultural viewpoint. The Karimojong are part of the eastern Nilotic people who form a different cultural group to both the Ganda and Basoga. These are ethnically and linguistically related Bantu people and respectively form the largest cultural groups in Uganda (UBS, 2009). The Ganda and Basoga live in quite peaceful and rapidly urbanising areas, and have better access to economic and employment opportunities and social services like health and education. Moreover, they are mainly agricultural producers and agriculture is a core sector of Uganda's economy; it employs 73% of the labour force (RoU, 2010). This situation is quite different from that of the Karimojong who are socially marginalised and are without access to public services.

Another vital difference between the psychiatric and Karimojong concepts of psychosis is that, in the latter, the experience of psychosis was associated with the afflicted individual's inability to use cultural symbols, namely *ebela* (walking stick) and *amakuk* (traditional stool). This is an example of what anthropologists call core symbols that express the shared values and beliefs (Peoples & Bailey, 2009; Lavenda & Schultz, 2008), and meanings (Eriksen & Nielsen, 2001; cf. Geertz, 1973) that enable members of a culture to interpret social behaviour. In medical anthropological discourse, however, it is argued that interpreting the nature of cultural symbols and their relationship to mental illness is controversial. This is because they are multivocal or polysemic; they have multiple meanings that can be linked to diverse life experiences and situations (cf. Helman, 1994; Turner, 1967, cited in Eriksen & Nielsen, 2001, p. 99). This is illustrated in Turner's work on medical beliefs among the Ndembu of northern Zambia. The Ndembu medical notions related psychosomatic distress with symbolic meanings. They also involve symbolic connections which depicted culture-specific issues and tensions in society (Turner, 1967, cited in Kleinman, 1980, p. 31). A wide range of medical anthropological literature supports and expands this analysis. An example of this research is Kleinman's conception of medicine as a cultural system in terms of both structure and functions. Kleinman argues that medicine, like culture, is a vast system of symbols that demonstrate the ways in which people think about illness and its suitable

treatment (Kleinman, 1980). In line with this conception, Helman has similarly argued that medicine is a symbolic system, which expresses some of the basic, underlying values, beliefs and moral concerns of the wider society (Helman, 1984).

In this context, the notion of a man moving with *ebela* (walking stick) and *amakuk* (traditional stool) might denote different things. First, these symbols can relate to the popular Karimojong tradition of herding. For instance, boys as young as five years often hold sticks while shepherding goats and sheep as practice for their adult roles as cattle herders (Stites, Akabwai, Muzurana, & Ateyo, 2007). Second, having a stick could also relay the cultural ideal of men being warriors, an art they are usually inducted into when they are as young as 15 years. This demands masculine qualities like displays of might and fearlessness. These in turn define the worth and enhance reputation of Karimojong young men (Peoples & Bailey, 2009). But the third meaning suggested by the data is that moving without *ebela* (walking stick) or *amakuk* (traditional stool) was seen as evidence of psychosis. This is a significant finding, supporting the view that lay concepts of illness do not simply name entities in the body, but also they describe other powerful images of the lifeworld. Thus, their interpretation must be grounded in everyday social processes of society (Good, 1994; Wiley & Allen, 2009).

Given the conceptual differences as discussed above, successful psychiatric diagnosis and treatment of psychosis in Karamoja requires understanding its meaning from people's viewpoint. It has been argued that combining emic and etic views makes psychiatric tools culturally sensitive and thus effective in identifying mental health issues in local settings (Kirmayer & Swartz, 2014; Patel, 2014a). I, too, would argue that the local concepts of psychosis can validate psychiatric tools and enable them to diagnose its experience, which is associated with heterogeneity and symbolism by the Karimojong. Otherwise, there is a risk of generating category fallacy; that is, the untenable belief that psychiatric diagnoses have the same validity and meaning in other cultures (Kleinman, 1977). This also seems to be true for depression, as I will subsequently demonstrate.

5.3.1.2. Depression

The local term *akiyalolong* described a condition which presented in adults who complained of having *ngatameta* (a lot of thoughts), *akiyoriwo* (sadness), and *akitam* (worries). Other

symptoms were silence and solitude. This is quite similar to the way psychiatry defines major depression (APA, 2013; WHO, 2007b). But similar to what has been reported in other African cultures (Betancourt et al., 2009; Hanlon et al., 2009; Kaaya et al., 2010; Okello & Ekblad, 2006), my study found that depression was seen as a non-persistent condition and was thus not treated.

In Dar es Salaam, Tanzania, Kaaya and colleagues (2010) found identical features of depressive illness: “thinking too much” (*kuwa na mawazo mengi*) and “extreme sadness” (*kusononeka*). Unlike the Karimojong, the Tanzanians related depressive illness to problematic pregnancies. Also, they ascribed their depressed mood to physical complaints or socio-economic difficulties, namely having bitterness in the heart/soul (*kujihisi uchungu moyoni/rohoni*) due to poor social support and not eating well because of lack of access to food, amongst others (Kaaya et al., 2010). These conditions made them feel vulnerable and anxious. It is only under very special conditions that depression was therefore expressed, while its experience seemed widespread in Karamoja.

The Ganda of south-central Uganda use the somatic idiom of *ebirowoozo/okweralikirira* (illness of thoughts) to describe depression. In this respect, depression is linked to having cognition (thinking too much), rather than emotional (sadness) problems (Okello & Ekblad, 2006). The Karimojong in contrast understood *akiyalolong* (“depressive illness”) to manifest in both disturbances of cognition (a lot of thoughts) and emotions (sadness and worries). The highlighting of the emotional aspects of depression by the Karimojong is linked to their experience of violent conflict and insecurity. They made this link when they related their feelings of terrible emotions and having worries to the stressful conditions they lived in. This suggests that the Karimojong ideas of depression are framed by both their culture and context. The Ganda in contrast have not been under threat of violence and have enjoyed relative peace for the last three decades.

The Karimojong concept of depression also compares to that of the war-affected Acholi in northern Uganda (Betancourt et al., 2009). The Acholi used the local syndromes of *two tam*, *kumu* and *par* to name depression. *Two tam* was described as having “lots of thoughts”. *Kumu* referred to experiencing extreme and persistent grief or sadness. *Par* was identified as a problem of having many worries. People with these syndromes showed diminished interest

in activities, fatigue, and feelings of worthlessness, including recurrent thoughts of suicide (Betancourt, 2009). Although the Acholi and Karimojong are both conflict-affected and neighbouring groups, they held contrasting notions about the categories of people who experienced depression in their respective communities. This may not be surprising as these are culturally and linguistically distinct people, who also subscribe to different livelihood systems. The Acholi are western Nilotics and agricultural producers. However, as described earlier, the Karimojong are eastern Nilotics and pastoralist producers.

More importantly, this further exemplifies some of the challenges involved in current global mental health understandings of the differential expressions of depression as embodied emotional experience (Kleinman & Good, 2010; Kleinman, 1988). While the articulation of such distress often combines emotional and somatic experiences, its recognition tends to be complex and problematic across cultures (APA, 2013; WHO, 2007b). The reason for this is that depression is a multi-dimensional condition. It can be experienced as mood or emotion, and as a symptom of mental illness. Yet it is also often diagnosed as a mental illness. But the relationships between these dimensions are complex and their interpretations often vary across different cultures (Kleinman & Good, 2010; Kleinman, 1988; Wiley & Allen, 2009).

In psychiatry, for instance, the diagnosis of depression involves more than people expressing basic emotions like sadness or misery. Depressed people are not only expected to feel miserable but also to have somatised symptoms such as tiredness and fatigue, loss of appetite, and a loss of interest or enjoyment (Kleinman, 1988; WHO, 2007b). But in a wide range of cultures, feelings of persistent sadness are usually seen as part of people's existential and spiritual experiences. Sadness or everyday unhappiness then tends to be seen as an unavoidable human experience of suffering. In this context, the expression of sadness is generally taken to signify a natural and expected reaction to life crises (Pilgrim, 2009). The data support and amplify this position in that the Karimojong do not see sadness as a specific marker of depression. It is instead interpreted as an expression of normal emotions towards everyday life problems like loss of cows to enemies, bereavement, and food scarcity.

The data also lend support to what Hanlon and colleagues found in their study of societal recognition of problematic distress states in the postnatal period and their relation to Western conceptualisations of postnatal distress in rural Butajira, Ethiopia (Hanlon et al., 2009). The

Ethiopians recognised and interpreted problematic distress conditions as comprising experiences of sadness, irritability, hopelessness and suicidal ideation. Although these features are similar to those used to define the psychiatric construct of postnatal depression, they were not associated with any specific illness experience. On the contrary, they were interpreted as normal reactions to social adversity and extreme poverty experienced by mothers during the postnatal period (Hanlon et al., 2009).

Consequently, the data suggest a need for validating the psychiatric concept of depression in this culture, which views it as part of its everyday reality. Failure to do so means that psychiatry may develop ineffective interventions that do not align with local needs, with the result that interventions may medicalise social suffering rather than addressing structural issues (Kleinman, 2000). In Karamoja, social suffering manifested in many forms: insecurity, extreme poverty, and chronic famine. That implies uncritical use of depression-focused psychiatric interventions could further disrupt the lives of people who struggle to survive in harmful social conditions. Next, I examine the local category of psychological trauma.

5.3.1.3. Psychological trauma

The local category *akibwal* described a cultural syndrome characterised by emotional and behavioural disturbances experienced by people who had been exposed to horrifying events like brutal arrests, torture, rape, and murder. This syndrome is related to psychological trauma, as described in research on war-related traumas in different parts of Africa (Igreja et al., 2008; De Jong & Reis, 2010; Reis, 2013), and in South Asia (Kohrt & Hruschka, 2010).

Among the Gorongosa people in post-civil war central Mozambique, the idiom of *gamba* defined as possession by spirits of dead male soldiers killed during the civil war was used to express suffering from war-related psychological trauma. Those mostly possessed by the *gamba* were women with personal or family experiences of extreme suffering such as involvement in forced labour, rape, and sexual slavery during wartime (Igreja et al., 2008). Like the Karimojong, the Gorongosa women's experience of those acts of violence and terror had serious negative effects on marital and gender relations in post-war times. In particular, women suffered marital conflict and gender violence, due to breakdown of trust with their spouses, who accused them of complicity in the perpetration of war atrocities (Igreja et al., 2008). This implies that interventions aimed at addressing psychological trauma in such

contexts can only be effective if they are sensitive to power and gender issues. A related idiom, describing the health effects of war violence recognised as attack by evil spirits, has been reported among the Acholi in post-conflict northern Uganda. The Acholi used the idiom of possession by *Cen* (spirits of killed persons/evil spirits) to explain the experience of psychological trauma (Reis, 2013). And similar to *akibwal*, *Cen* also manifested with other culturally significant features like having nightmares, images of violence, disturbing recollections of witnessed violence, and insomnia. However, the syndromes of *akibwal* and *Cen* were viewed differently by the respective cultures. For the Karimojong, *akibwal* symbolised widespread and collective emotional suffering. Conversely, the Acholi believed that *Cen* causing spirits tended to afflict murderers, but could also attack anyone crossing their path in their unhappy roaming. For this reason, *Cen* was regarded as highly contagious, feared, and as a consequence stigmatised by the Acholi (Reis, 2013).

Furthermore, a local construct of psychological trauma comparable to *akibwal* in Karamoja has also been found among the Balanta in post-war southern Guinea Bissau in West Africa (De Jong & Reis, 2010). It was described as the *kiyang-yang*, an illness attributed to people's exposure to extreme violence, terror, and precarious living conditions. These included war, bombardments, human rights violation, and social marginalisation. However, the authors found that the idiom *kiyang-yang* also had important political dimensions and functions. It was used as a cultural symbol of protest by the Balanta against state repression in post-war times. This view points to the need for contextually sensitive analysis of idioms of distress. Such analysis expands understandings of metaphoric language that describes suffering, which people cannot express otherwise due to its inherent threat to the oppressive power structures that surround them (De Jong and Reis, 2010). For the Karimojong the idiom *akibwal* similarly expressed their resentment of their oppression and disempowerment by the state.

The local category *akibwal* also overlaps with what Kohrt and Hruschka (2010) identified among trauma survivors in Kathmandu, Nepal. The Nepalis used the term *piDaa* and the corresponding term *maanasik piDaa* to name psychological trauma. They described *PiDaa* as suffering or torment while the syndrome *maanasik piDaa* referred to mental anguish. And as was the case with *akibwal*, these syndromes were similarly defined by emotional and somatic disturbances. These were identified as *manmaa kura kheln* (having worries playing in their heart-minds), *jhajhalko aauchha* (flashbacks, flickering memories), insomnia, and headaches.

I conclude this sub-section with an examination of Karimojong cultural constructs of epilepsy and intellectual disability.

5.3.1.4. Epilepsy as *Akirakara* and Intellectual disability as *Ngibangibangi*

In Karamoja, epilepsy was called *akirakara*, which was defined as a childhood mental illness presenting with frequent and sudden falls, fainting or loss of consciousness, drooling and frothing at the mouth. This understanding of epilepsy is in line with that of many cultures in different regions of the world (Carod-Artal & Vázquez-Cabrera, 2007; Keikelame & Swartz, 2013; Orley, 1970; Whyte, 1995), but there are differences as well.

Among the Ganda people in central Uganda, epilepsy was also recognised as mental illness, and was given the name *ensimbu*. It was also recognised by the Ganda as presenting with *grand mal* seizures that caused sudden falls, unconsciousness and jerking of the afflicted person's body. People with *ensimbu* were also said to urinate, froth at the mouth and bite their tongues, and to sleep for as long as an hour. But upon regaining consciousness, they could not remember the event (Orley, 1970). Current results are also confirmed by Whyte (1995), who found that participants in Morogoro and Kilimanjaro (Tanzania) used the local idiom of *kifafa*, which translated as “little death” to describe epilepsy in children. She found that *kifafa* was a familiar childhood illness and better known than psychosis or intellectual disability amongst children. In addition, *kifafa* was explained as the sickness that occurred with the same basic features as those reported by the Karimojong. Furthermore, in South Africa, the Xhosa people also recognised epilepsy in the same way as the Karimojong. It was called *isifo sokuxhuzula* and *isifo sokuwa*, which mean an “illness of fitting” and an “illness of falling” respectively. And, those with epilepsy were also said to bite their tongue during violent attacks. Unlike the Karimojong, however, the Xhosa protected people with epilepsy from biting their tongue and swallowing it (Keikelame & Swartz, 2013).

The Karimojong understanding of epilepsy also resonates with the interpretation of the experience of Native American people (Carod-Artal & Vázquez-Cabrera, 2007). The Tzeltal Maya people in Chiapas (Mexico) termed epilepsy as *tub tub ik'al*, which means a “person that breathes anxiously or shocking”. The Kamayurá people in Matto Grosso State of Brazil called epilepsy *teawurup* or *armadillo's disease* that was named after a nine-banded armadillo (*tat'u* or *Dasypus novemcinctus*), which in that culture was taboo to hunt or kill.

And, among the Ura Chipaya people in the Bolivian Andes epilepsy was given the name *tukuri*. However, all the three cultures in common defined epilepsy in terms of having convulsions, sudden falls, and foaming at the mouth.

With regard to intellectual disability, it was culturally described as *ngibangibangi*, which means a condition presenting in children who were unable to understand things and express normal feelings in specific situations. This corresponds to the psychiatric definition of intellectual disability (APA, 2013; Bigby & Frawley, 2010). Research on lay conceptions of intellectual disability in Uganda is not available. However, studies in other African settings such as Ghana (Avoke, 2002; Kpobi & Swartz, 2018) and Tanzania (Kisanji, 1995), and in the Philippines (Brolan et al., 2014) have reported local concepts of intellectual disability similar to *ngibangibangi*.

As described in Karamoja, research in Ghana has also found that the experience of intellectual disability is primarily associated with impairment of the mind (Avoke, 2002; cf. Kpobi & Swartz, 2018). The Akan people in southern Ghana describe people with intellectual disability as *nea wanyin agya n'adwene ho* (“the one who is retarded” or “the one who has outgrown his other brain”). Among the Ewe people of south-eastern Ghana, children with intellectual disability are termed as *susudidivi* (children with reduced mental functioning), and *asovi* (“a fool or an idiot”), and as *tagbomadetowo* (“someone with reduced intellectual abilities”). And, among the Ga people of eastern Ghana, the term *buluu*, meaning “fools” is used to describe people with intellectual disability. Close to Uganda, research in Tanzania has found that there are proverbs used, which carry a concept related to intellectual disability. The Tanzanians used the concept of *ujinga*, which denotes “stupidity” or “foolishness” to refer to intellectual disability, and associated its experience with impaired social functioning (Kisanji, 1995).

In addition, a cultural construct of intellectual disability akin to *ngibangibangi* has been described among Filipinos in Negros Occidental province (the Philippines). The Filipinos identified intellectual disability as *tuob*, which was believed to be caused by supernatural powers. Specifically, its experience was attributed to disturbance by evil spirits, which afflicted people due to anger or vengeance. And, the interpretation of *tuob* (intellectual disability) as a magico-spiritual illness influenced the local response strategies for its

treatment. Thus, the main source of cure for *tuob* was the *suranho* or folk healer (Brolan et al., 2014).

This sub-section has examined the Karimojong cultural concepts of mental illness in the context of psychiatric nosologies of psychosis, depression, psychological trauma, epilepsy, and intellectual disability. Next, I discuss ideas about causation of mental illness.

5.3.2. Ideas about causation of mental illness

In this sub-section, I move on to Kleinman's notion of causation of illness to discuss the ideas about causation of mental illness held by the Karimojong. In the literature, the notion of causation refers to people's understandings and explanations of the aetiology (causes) of illness and other forms of misfortune. It thus relays the ideas (or beliefs) which people hold regarding the origins of illness and its significance. These ideas significantly influence health-seeking behaviour and the pragmatics of choice of care (Hergenhahn, 2009; Kleinman, 1980; Lefley, 2010; Swartz, 1998).

5.3.2.1. Explanatory ideas about psychosis-like cultural syndromes

When faced with the experience of psychosis, the Karimojong considered these experiences to be a result of actions of different supernatural agents. These agents were described as *akuj* (God), *atapapaa* (ancestor spirits), *ngicen/ngawuyonito* (the spirits of dead people or ghosts), *ngilam* (curses), and *akisub l'thuam* (bewitchment). Similar findings have been reported in available studies on explanatory models of psychosis in Africa. In particular, there is a widespread belief regarding the role of supernatural factors in causation of psychosis in many African cultures (Abbo et al., 2008; Adewuya & Makanjuola, 2008; Ikwuka et al., 2013; Okello & Musisi, 2006; Patel, 1995; Patel et al., 2007; Teuton et al., 2007). However, in Karamoja, explanations of mental illness through the spiritual agents described above also speak to other important social aspects of their society.

The Karimojong believe that when the cause of psychosis was not known then it was *akuj* (God) or *akisub l'thuam* (bewitchment) that brought such illness. Some studies have reported that people who hold strong religious values are likely to explain their experience of severe mental illness in terms of spiritual causes because they see it as a consequence of moral dissonance (Bhui et al., 2002, cited in Ikukwa et al., 2013, p. 4; cf. Kleinman, 1988). This is

also echoed by my results. For instance, the experience of psychosis was thought to reflect shared moral challenges faced by sufferers and their families, which also confirms the notion that social suffering is a critical indication of moral order in society (Kleinman, 1988).

Kleinman has argued further that in the familial context of close relations, mental illness is unlikely to be thought of as a misfortune for the afflicted person only. Such suffering instead becomes a collective experience. This is because the locus of suffering caused by mental illness in a family is situated in an intersubjective space shared by everyone in that social domain (Kleinman, 1988). Several studies have, on the contrary, concluded that beliefs in witchcraft as a cause of serious illness like psychosis often speak to the uneasy tensions and contradictions in social relations within specific cultures (Helman, 1994; Lock, 1993; Rasmussen, 2008; Reis, 2013; Wiley & Allen, 2009).

However, my research further indicates that both *aku* (God) and *akisub l'thuam* (bewitchment) were used by the Karimojong as residual explanatory categories (Hammond-Took, 1989; cf. Helman, 1994) of psychosis. Such a category offers an explanation of last resort for misfortune or serious illness. That is, it is used by people to explain suffering in terms of fate, which they cannot control or change. In a study in rural South Africa, Hammond-Took shows that the diagnosis of illness and misfortune was ascribed to “God” when there was no precise physical or social cause. In this respect, he argues that compared to current bio-medical explanations of illness, such spiritual explanations are akin to the scientific notion of chance or coincidence. In scientific parlance, a coincidental observation cannot be sensibly explained (Hammond-Took, 1989; cf. Helman, 1994). In trying to further clarify this view, Helman has observed that as much as spiritual explanations for illness may appear to be less common in high-income settings such as Britain, they are expressed in various idioms like “bad luck,” “fate,” “the stars,” or “an act of God,” which people frequently use to explain illness (Helman, 1994, p. 127).

With regard to the explanatory category of *atapapaa* (ancestor spirits), the spirits were believed to cause the suffering of psychosis if they became upset by the living due to their engaging in unacceptable behaviour. Such behaviours, for example, involved the refusal by the living to perform their social and cultural obligations to ancestors. This belief is closely related to the ideal of upholding good relations and harmony with ancestors, which is widespread in many parts of Africa (Okello & Ekblad, 2006; Orley, 1970; Patel, 1995;

Rasmussen, 2008). Yet, *atapapaa* (ancestor spirits) were also thought to make some people to suffer psychosis through spirit possession. In such a case, however, the suffering of psychosis was seen as an indication of ancestral calling. In this respect, the notion of spirit possession by *atapapaa* (ancestor spirits) among the Karimojong is no different from that of *ukuthwasa* among the Xhosa of South Africa (cf. Sordahl et al., 2010; Swartz, 1998), and *dzosa* among the Gorongosa of Mozambique (Igreja et al., 2008), which also speak to how people get to know about becoming a healer.

The *ngilam* (curses) spiritual explanation also had a dual function. It accounted for the aetiology of psychosis and also communicated issues of power and authority in Karimojong society. The Karimojong, like other nomadic pastoralists of Africa, are traditionally governed by a complex gerontocracy. That is, a political system where the control of power is vested in older men (Czuba, 2011; Novelli, 1988; Sundal, 2009). In Karamoja, the *ngikasikou* (elders) exert substantial power, which manifested in the everyday political and spiritual functions they perform. In explaining the significance of the *ngikasikou*'s (elders') power, participants described them as important people, who acted as intermediaries with divinity. In this context, it was reported that they interceded in everyday life difficulties. More importantly, they could promote the health and well-being of others through *arerengu* (blessing) them, on the one hand. On the other hand, the *ngikasikou* (elders) also placed *ngilam* (curses) on people to suffer illness if they wilfully engaged in culturally inappropriate behaviours. These behaviours include transgression of cultural taboos, dishonesty, and disrespect, amongst others. Such beliefs have been reported to be widely practiced in Africa, especially among nomadic pastoralist populations. For instance, among the Samburu nomads of Kenya, who share many aspects of social organisation with the Karimojong, serious illness such as psychosis is also attributed to the dynamics of curses. And cursing is also viewed as a form of cultural sanction, which can bring severe illness and misfortune for even minor transgression (Spencer, 2004 [1965]). So, as in Karamoja, the fear the power of the curse by the Samburu has the social and psychological effect of promoting conformity to cultural norms and mitigating conflict. In doing so, it regulates moral conduct while at the same time upholding social order. More importantly, such a belief illustrates how people's psychologies are influenced by the socio-political structures of their society (cf. Scheper-Hughes, 1992).

5.3.2.2. Explanatory ideas about depression and psychological trauma

The causes of *akiyalolong* (“depressive illness”), which was defined as the experience of having a lot of thoughts, sadness, and worries, were considered to be social and contextual factors. These factors include the experience of persistent violence and insecurity, frequent loss of livestock, food scarcity, and bereavement. However, the Karimojong held the view that this was a non-persistent condition, implying that it could resolve once the conditions causing it were eliminated. These results are confirmed by previous qualitative studies of depression conducted in Africa (Okello & Ekblad, 2006; Ventevogel et al., 2013), and in other developing countries such as India (Pereira et al., 2007), which have reported that depression is often attributed to the experience of adverse social circumstances. In addition, that it was not often regarded to be a serious mental illness and was rarely treated.

Among the Ganda of south-central Uganda, similar factors were believed to contribute to the suffering of depression as in Karamoja. The Ganda described the major factors that predisposed people to suffering of depressive illness as marital and relationship conflicts. And these conflicts were associated with lack of resources, mainly engendered by poverty. Yet, the Ganda thought that there was no medicine for depression or “illness of thoughts”, as they described it (Okello & Ekblad, 2006). In Burundi, participants linked their exposure to *ibonge/akabonge* (depression) to experiences of loss of livelihood and properties, bereavement, and living in miserable conditions that included poverty. Burundians also included among their explanations of depression the concept of being confronted with family problems. Such problems included divorce and having too many responsibilities (Ventevogel et al., 2013). Related views concerning causal explanations of depression have been documented in India. Pereira and colleagues described the risk factors for the suffering of depression as having economic difficulties and difficulties with interpersonal relationships, especially those related to marital relationships. Thus, similar to the Karimojong, participants in India conceptualised the aetiology of depressive symptoms as a consequence of socio-economic and interpersonal difficulties that characterised their social world (Pereira et al., 2007).

In describing the suffering of *akibwal* (psychological trauma), the Karimojong attributed the condition to their exposure to terrifying psychosocial causes. These include violent arrests, torture, murder and rape. This is in line with explanations in other studies in settings affected

by war and conflict in Africa and elsewhere in the world that have mostly attributed the suffering of psychological trauma to psychosocial factors (De Jong & Reis, 2010; Igreja et al., 2008; Kinyanda et al., 2010; Kohrt & Hruschka, 2010). However, in their explanations, the Karimojong also highlighted the ways in which *akibwal* embodied social suffering that resonated with their long-term experience of a dominant and oppressive social order. In particular, they described *akibwal* as widespread and collective suffering, which was closely linked to the vicious social and political conditions of their society: armed violent conflict, insecurity, extreme poverty, and chronic famine, amongst others.

The Karimojong lay explanations of psychological trauma have potential implications for psychiatric management of this condition in Karamoja. The explanations highlight some of the complexities involved in understanding and interpreting psychological distress associated with living in a context of extreme violence and related structural disruptions. In examining these complexities, Swartz (2015a) calls attention to a more conscious and critical analysis of violence and its traumatic consequences. As an explanatory category of mental suffering, Swartz (2015a) argues that interpreting violence only in terms of direct assaults on the body that may range from beatings to rape, is a minimalist and less helpful way of understanding its impacts on affected people's mental health. Instead, the phenomenon of violence, which includes indirect violence – structural violence – as described by medical anthropologists (Kleinman, 2000; Rylko-Bauer & Farmer, 2016; Scheper-Hughes, 1992), must be understood broadly and more holistically. This helps to expand and deepen our understanding of mental health issues linked to the lived experience of extreme violence (Swartz, 2015a). In this sense, structural violence refers to various processes and mechanisms, which cause social suffering. These include discrimination, dispossession, disenfranchisement, forced removals and confiscation of land and property, humiliation and denigration, amongst others (cf. Rylko-Bauer & Farmer, 2016; Swartz, 2015a). In this context, the Karimojong lay explanations of psychological trauma – *akibwal* – seem to reflect embodied effects of their social suffering due to long-term political marginalisation, economic neglect and cultural isolation by the state. So, to be effective, interventions aimed at prevention and treatment of psychological trauma in Karamoja would need to address both individual and collective causes and consequences of suffering. They, in turn, could deal with what is socially and culturally at stake for the sufferers of *akibwal* in particular and the Karimojong in general.

5.3.2.3. Explanatory ideas about epilepsy and intellectual disability

The causes of epilepsy and intellectually disability, which were described as childhood mental illnesses, were believed to be largely supernatural in nature, but also to some extent biological. The supernatural related causes that were described were quite similar to those attributed to the suffering of psychosis: curses (i.e., intergenerational), bewitchment, attack by malevolent spirits/ghosts. In addition, *elomanu* (adultery/immoral sexual conduct), *ekinyit* (“a bird of bad omen”) and “evil eye” were also regarded as aetiologies of epilepsy and intellectual disability. The recognition of these supernatural and cultural factors as important factors in the causation of epilepsy and intellectual disability has also been reported in studies conducted in parts of Africa (Adjei et al., 2013; Keikelame & Swartz, 2013; Kpobi & Swartz, 2018; Winkler et al., 2010), and elsewhere in the world (Brolan et al., 2014; Carod-Artal & Vázquez-Cabrera, 2007).

In northern Ghana, the aetiologies for epilepsy were described in a similar way to that of the Karimojong. Epilepsy was perceived by Ghanaians to be a contagious disease which was caused by transgression of cultural taboos, and the malign actions of spiritual agents. Moreover, it was also explained as punishment for some sorts of social wrongs such as pregnant women taking a bath at night or committing adultery in the bush (Adjei et al., 2013). In the case of intellectual disability, a study in the Greater Accra Ghana found that although its causes were believed to be mainly biological, it was also attributed to spiritual factors. The spiritual causes included avaricious spirits, jealousy and envy, and curses (Kpobi & Swartz, 2018). In my research, although children’s suffering of epilepsy and intellectual disability was attributed to supernatural dynamics, it was believed they were only indirect victims. The actual targets were their parents. This again may reflect lack of knowledge about the actual causes of these illness, as was the case with ascribing psychosis to acts of bewitchment and God. Further south, the Xhosa people in Khayelitsha in South Africa recognised evil spirits (*amafufunyane*) and bewitchment, among other factors as causes of their children’s suffering of epilepsy (Keikelame & Swartz, 2013). And, among the Iraqw and Dakota people of northern Tanzania, epilepsy was also commonly thought to be caused by spiritual factors such as witchcraft, sorcery, taboo breaking, and possession by evil spirits (Winkler et al., 2010).

In the Philippines, intellectual disability is seen as a magical, spiritual illness. In particular, its origins were ascribed to affliction by evil spirits, due to annoyance or vengeance (Brolan et al., 2014). The Kamayurá people in the Matto Grosso State of Brazil also held magical and religious concepts of epilepsy. They recognised epilepsy as a chronic disease caused by the revenge of the spirit (*mama'e*) of the *armadillo* killed by a huntsman or fisherman. According to Kamayurá tradition, epilepsy usually originated when a nine-banded armadillo is hunted and killed. The Kamayurá believed epilepsy (*teawarup*) appeared when a huntsman killed a nine banded *armadillo* (*tat'u* or *Dasypus novemcinctus*) by using an arc and arrows. The spirit of the dead animal could attack the hunter at night, while he was sleeping, and afflict him with epilepsy (Carod-Artal & Vázquez-Cabrera, 2007). In addition, it was believed that epilepsy (*teawarup*) could also appear during childhood. In this case, just like in Karamoja, it was thought that the father of the child with epilepsy hunted an *armadillo*, and that the spirit of the *armadillo* brought by the arc and arrows attacked the hunter's son during his dreams. One interesting difference in the beliefs of these two cultures is that among Kamayurá, unlike the Karimojong, epilepsy (*teawarup*) was recognised as an illness experienced by both young and elderly people (Carod-Artal & Vázquez-Cabrera, 2007).

Further, the results revealed that in addition to the supernatural/cultural explanations, the Karimojong also held biological views regarding the suffering of epilepsy and intellectual disability. As we have seen, the source of these illnesses was thought to be genetic, particularly if there was a history of such illness in the afflicted child's family. In addition, it was believed that injuries from physical trauma suffered during a difficult birth could expose children to such illness. Biological explanations for epilepsy and intellectual disability have also been observed in other African cultures (Kpobi & Swartz, 2018; Winkler et al., 2010). In Ghana, for example, intellectual disability was considered to be a genetic condition (Kpobi & Swartz, 2018), as occurred in Karimojong culture. Some studies have suggested that biological views held by local people regarding the aetiology of neurological illnesses like epilepsy and intellectual ability may be a reflection of their proximity and contact with bio-medical services (Winkler et al., 2010). This is also reflected by my results. Specifically, the Karimojong who attributed children's suffering of epilepsy to biological factors were those I spoke with in Nadunget and they indicated that they sought treatment from the bio-medical health centre in Moroto town. The results further indicate that some mothers made efforts to attend bio-medical antenatal clinics but access to such services was extremely difficult. This

suggests that some mothers could have perceived bio-medical care as helpful in ensuring safe deliveries.

In this section, I have examined Karimojong explanatory ideas regarding the causes of mental illness: psychosis-like cultural syndromes, depressive illness, psychological trauma, and epilepsy and intellectual disability. In the subsequent sub-section, I discuss the local views about the course and effects of mental illness.

5.3.3. Impact and course of mental illness

In this sub-section, I draw on Kleinman's concept of expected course of sickness to discuss Karimojong's interpretations of the impact and course of mental illness. According to Kleinman, the concept of expected social course of sickness or illness reveals the significance of a given illness for the sufferers and their families. In doing so, it also helps to disclose the particular kinds of social problems and tensions, which may be associated with the causes of suffering (Kleinman, 1980).

For the Karimojong, the impact of suffering mental illness reflected in the numerous social and health difficulties which confronted the sufferers and their families. These difficulties mainly involved being confronted with negative societal attitudes, stigma and discrimination as well as dispossession or loss of resources. And these experiences commonly affected those with conditions thought to be incurable and yet associated with severe impairment in functioning, namely psychosis, epilepsy and intellectual disability.

5.3.3.1. Exposure to negative attitudes, stigma and discrimination

The association between suffering severe mental illness and being exposed to negative societal attitudes is well demonstrated in the literature (Callard et al., 2012; Chandra et al., 2012; Mehta & Thornicroft, 2014; Link & Phelan, 2006; Reavley & Jorm, 2011). The Karimojong considered people with psychosis and the sufferers of epilepsy to be violent and dangerous people. In particular, they were thought to be harmful to others and even themselves. And, they were perceived as people who could not reason. These beliefs of violence and fear of people with severe mental illness contribute to their stigmatisation and discrimination or social exclusion (Callard et al., 2012; Kleinman, 2009).

Stigmatisation of people with serious mental illness such as psychosis often occurs through the use of negative stereotypes that link their experience to socially undesirable behaviours and characteristics (Link & Phelan, 2006; cf. Rüsch & Corrigan, 2013). This is confirmed by current results. In Karamoja, people with psychosis were regarded as socially disordered people, and also thought to have lost their humanity, value and dignity. This was exemplified by the use of negative stereotypes: *ekaakiding* (useless male person) and *akaakiding* (useless female person) to describe male and female adult sufferers of psychosis respectively. These stereotypes were thus used to mark sufferers as non-persons or non-human (Kleinman, 2009).

It has been argued that in order to survive and develop, societies need people who function (Allotey & Reidpath, 2007). This means that an individual's ability to function is critical to her being regarded as a worthy member of her society. More importantly, the individual exercises that ability by engaging in reciprocal exchange with others based on social constructs such as life stage or age, gender, and health status, amongst others (Allotey & Reidpath, 2007). In this regard, the use of these demeaning identities (Link & Phelan, 2006) by the Karimojong to describe people with psychosis seems to partly reflect the difficulties of survival in their society. As we have seen, life in Karamoja is so uncertain and difficult due to various structural problems: violent conflict, insecurity, extreme poverty, and chronic famine. So, everyone has to struggle and contribute towards meeting everyday life needs. Consequently, it would appear that people with psychosis were described as useless or as no longer being of any value because they were deemed to lack the capacity to participate in everyday life and survive.

From a human rights perspective, however, when people with mental illness are no longer regarded as fully human, they become targets for abuse, discrimination and rejection. As a result, they are unable to fully participate in society (Kleinman, 2009; Mehta & Thornicroft, 2014; Randal et al., 2012). The results confirm that this was also the case in Karamoja, where people with severe mental illness faced profound social exclusion, marginalisation and human rights abuses. For example, people with psychosis and their relations were excluded from participating in cultural institutions like the *akiriket* (sacred assembly for the elders). And yet, it was in this assembly that the Karimojong made the most important decisions about the issues that affected their life. This also seems to confirm the view that discrimination tends to blight the social life of people with mental illness. That is, they

experience a lack of protection from the most basic infringements of their dignity, personal rights, even life itself (Randal et al., 2012; Kleinman, 2009). Kleinman has argued that discrimination of people with mental illness subjects them to the experience of dehumanisation or sociomoral death. This is largely because sufferers are deprived of their roles as “effective nodes in the network of connections that form social life”. More fundamentally, they experience social inefficacy, which means non-participation in social reciprocity, including gift exchange. Yet, social reciprocity is “the fundamental cultural process of living an ordinary life”. As a result, sufferers are denied participation in the basic social domains such as marriage, work, education, celebrations, festivals, mourning rituals as well as in ordinary experiences like in markets and in other everyday life activities. Therefore, to be confronted with such experiences of violence, exclusion, discrimination and humiliation, Kleinman further argues, is “to be treated as if one didn’t exist” (Kleinman, 2009, p. 604).

In the case of children with epilepsy, they were not allowed to attend social activities such as prayers nor play with others. This is because their behaviours were considered to be impulsive. In addition, they were excluded from having social relationships with other children because of fear that epilepsy was contagious. Consistent results have been reported in developed countries such as in Britain and Canada (Kerr et al., 2011), and in developing countries like Tanzania (Jilek-Aall, Jilek, Kaaya, Mkombachepa, & Hillary, 1997; Winkler, et al., 2010).

In Britain and Canada, children with epilepsy reported suffering psychological violence because of being exposed to negative and rejective attitudes at both home and school. The attitudes of other people manifested in various actions that involved teasing, talking about, laughing at and bullying afflicted children. In addition, the children were stereotyped and treated differently to their siblings and peers by significant others, including parents and teachers. For instance, the parents never allowed afflicted children to leave home while the teachers restricted them from taking part in outdoor activities at school (Kerr et al., 2011).

Among the Iraqw and Datoga people of northern Tanzania and the Wapogoro people of southern Tanzania, children with epilepsy have also been found to be denied engaging in social activities with others (Jilek-Aall et al., 1997; Winkler et al., 2010). The Wapogoro

parents of children without epilepsy withdrew them from schooling once they learnt that a child with epilepsy had a seizure in the classroom or the school yard. The Wapogoro removed their children from school due to the fear that they would catch epilepsy. Further, children with epilepsy were also forced to drop out of school because of stigma. Yet, even those children who became seizure-free after receiving treatment would rarely be re-admitted to school (Jilek-Aall et al., 1997). In the case of Karamoja, though many people consider formal education to be irrelevant to their livelihoods (Stites et al., 2007) and thus do not send their children to school, children with epilepsy were never given the chance to attend school. This is because they were thought to be unable to socially function in society. Moreover, like the Wapogoro, the Karimojong held the fear that epilepsy was a relentless and incurable illness.

However, the results further indicate that besides being refused the chance to participate in everyday life activities, the stigmatisation and discrimination of people with psychosis and children with epilepsy had wider implications for social relations among the Karimojong. In particular, this impacted negatively on familial and marital relations. With regard to familial relations, the experience of psychosis was interpreted in moralised terms. For example, the experience of psychosis in a family was seen as punishment for bad morals and antisocial conduct. This is in keeping with what has been found among Ghanaians (Quinn, 2007). The attitudes of Ghanaians towards people with mental illness and their families were found to be poor and discriminative. However, there were variations in the exposure of the afflicted people and their families to such experiences by social and geographical contexts. Ghanaians living in urban areas held more stigmatising attitudes towards mental illness than their counterparts in rural Ghana. The difference in stigmatisation and discrimination against people with mental illness between the local communities in urban and rural Ghana was linked to the [non-] existence of kinship ties. For instance, kinship ties were reported to be absent among urban communities while they were found to be stronger in rural areas.

Despite it being expected that stronger kinship ties exist among the Karimojong because they are still a predominantly rural people, it seems these ties are being eroded by structural forces. As we have seen, factors such as persistent insecurity, famine and deprivation have constantly diminished people's capacity to cope with distress. This in turn has made life so precarious (Green, 2008; WHO, 2007a). A clear example is when the Karimojong talked of how people with psychosis had the poorest access to food. Surprisingly, even interventions

like the distribution of food aid by the WFP did not explicitly provide for them. Despite targeting the “most vulnerable” people like malnourished children, the elderly and people with disabilities, there was no mention of people with mental illness. And yet, not everyone who was willing to access food through *ikwa lounoi* (food for work scheme) was receiving food. As such there were many people who could not meet the food needs of their families. This suggests that the psychosocial context plays a significant role in influencing the nature of kinship ties. Probably, the situation for people with psychosis in Karamoja would have been less severe if they were living in better conditions.

Another important social institution negatively impacted by the experience of mental illness in the family is marriage. The Karimojong believed people with mental illness were not eligible for marriage. As a result, the onset of severe mental illness for people already married led to separation and abandonment by their spouses. The challenge of failure to marry by people who experienced premarital mental illness was described by participants in two instances. In the first instance, other people avoided marriage with adults with psychosis and those from families with children suffering mental illness because they believed that mental illness was an intergenerational illness. Thus, to marry someone with mental illness or from a family with a history of mental illness was seen as one of the ways of bringing mental illness to a family without such a history. In the second instance, people with mental illness, especially females, could not be married. This is because they were expected to have serious difficulty in performing social roles, especially in keeping a home and raising a family. These findings reflect those of previous studies (Breslau et al., 2011, cited in Kessler et al., 2014; Chandra et al., 2012) in other regions of the world, indicating high rates of failure by people with premarital psychosis to be married.

The data suggest the need to implement interventions that can address stigma, discrimination and human rights abuses among people with mental illness in Karamoja. Research has shown that stigma is a complex social phenomenon. It is linked to three interrelated elements: a problem of knowledge (i.e., ignorance and misinformation); a problem of negative attitudes (prejudice); and a problem of rejecting and avoidant behaviour (discrimination) (Link & Phelan, 2006; Mehta & Thornicroft, 2014). This suggests that the experience of stigma engenders discrimination that results in violations of human rights, which in turn legitimates stigma (Randal et al., 2012). Given these looping interactions, the quality of life of people

with mental illness in Karamoja is unlikely to be improved by use of psychiatric treatments alone. Such interventions should be accompanied by strategies that can reduce stigma and discrimination and promote human rights. One such strategy could be to improve mental health literacy among the Karimojong. Mental health literacy refers to public knowledge and beliefs about mental health (Jorm et al., 1997). This could be realised by using different approaches, such as social marketing campaigns. Such campaigns have been used in high-income countries such as Britain and New Zealand to inform and educate the general public about mental illness and its treatment, and have been found to be successful in those countries. Specifically, they have been found to produce positive changes in public attitudes towards people with mental illness. As a result, they have contributed to a substantial reduction in the stigma and discrimination associated with suffering mental illness (Mehta & Thornicroft, 2014).

5.3.3.2. Dispossession/loss of resources

One of the adverse impacts faced by adults with psychosis in Karamoja was the loss of access to resources. As earlier stated, although the majority of the Karimojong were living in dismal socio-economic conditions, the situation of adults with psychosis was worse than that of other people. They were the most deprived individuals in their society for two important reasons: denial of entitlement and dispossession. The denial of entitlement occurred in the context of adults with psychosis not being given a share of their family estate, and this particularly referred to cattle. Yet, ownership of cattle was the basis for earning a livelihood in Karamoja. It was thought that giving adults with psychosis cattle would be a waste of resources since they were deemed indisposed and lacking ability to productively make use of them. Similarly, adults with psychosis suffered dispossession through theft of cattle already in their possession by enemy raiders. Given the complex and precarious conditions of life in Karamoja, the above scenarios seem to reflect the harsh realities of survival by the poor people in the region (cf. Green, 2008).

However, this may also be a reflection of the wide recognition that affliction with severe mental illness such as psychosis leads to loss of human productivity and social functioning (Bedirhan 1999; Golightley, 2008). In addition, this also confirms the notion that people with psychosis in conflict and humanitarian settings do not only lose access to resources but also suffer further neglect and vulnerability. In this sense, they are deprived of the resources that

would enable them to regain functioning (Jones et al., 2009; Tol et al., 2011). But it is important to note that denying entitlement of adults with psychosis to their family estate was likely to further complicate their misery by keeping them in perpetual poverty. It would also make it difficult to give care and support and to protect the human rights of adults with disabilities (Patel et al., 2018).

The relationship between the experience of social disadvantage and extreme poverty and suffering mental illness is well established (Eaton et al., 2010; Lund et al., 2018; Patel & Kleinman, 2003; Perry, 1996). These studies have shown the close association between poverty and the risk and prevalence of mental illness in different regions of the world. Specifically, they have shown that people with less economic and social power tend to suffer an increased burden of mental illness and related forms of disability. In analysing how SDGs are pertinent to addressing the social determinants of mental illness, and how these goals could be optimised to prevent mental illness, Lund and colleagues have observed that pathways between poverty and mental illness are complex and bidirectional. Living in poverty is not only a major predisposing risk factor for suffering mental illness, but being poor is also closely associated with other social determinants of mental illness. Conversely, living with mental illness also exposes sufferers to the experience of poverty and related forms of suffering (Lund et al., 2018). In other words, experiences of poverty and mental illness perpetually interact and mutually reinforce each other. And this results in a vicious cycle of poverty and mental suffering. This is not only reflected in my findings, but also they provide new evidence on the recognition of the ways in which experiences of psychosis and deprivation mutually influence each other, especially from the perspective of nomadic pastoralists.

From a political economy perspective of suffering, exclusion of people with mental illness, combined with dispossession, therefore, appear to reveal the harmful consequences of structural violence, which the social order in Karamoja holds for them and their families (Kleinman, 2009; Rylko-Bauer & Farmer, 2016). This is illustrated through the Karamoja's long history of experience of active political marginalisation by the state. Such a history of marginalisation manifests through being confronted with the preventable challenges of extreme poverty, chronic famine, poor health, poor infrastructure and lack of access to basic social services. As a result, the Karimojong lack access to the basic resources that they need

to maintain health and well-being (Office for the Coordination of Humanitarian Affairs, 2011; WHO, 2007a). However, this situation is avoidable if the state took its responsibility seriously and made conscious efforts to address the root causes of those multiple adverse social conditions or dimensions of structural violence, which the Karimojong embody and express as illness and social suffering (cf. Rylko-Bauer & Farmer, 2016).

This sub-section has discussed the local views about the course and effects mental illness. In the next sub-section, I examine the question of treatment of mental illness in Karamoja.

5.3.4. Treatment of mental illness

In this sub-section, I discuss the question of treatment of mental illness among the Karimojong following Kleinman's concept of desired therapy for an illness. As Kleinman points out, EMs offer explanations for illness and treatment to guide the choices people make among therapies and therapists (Kleinman, 1980). Given that no theme emerged from the data regarding health-seeking for psychological trauma, the discussion will focus on treatment of psychosis-like syndromes, epilepsy and intellectual disability, and depression.

5.3.4.1. Treatment of depression

While there was similarity in the defining features of major depression and the local syndrome of *akiyalolong*, this syndrome was not seen as a persistent health problem and thus was not treated. In this context, it was mainly managed through the lay system of care that included relatives, friends, and other significant others, who extended emotional and social support to those affected. This is similar to what has been reported in other African cultures (e.g., Okello & Ekbald, 2006 in Uganda; Ventevoget et al., 2013 in Burundi, Kaaya et al., 2010 in Tanzania, and Hanlon et al., 2009 in Ethiopia). These studies also reported that depression was not seen as a medical problem in need of treatment, and as a result management was primarily psychosocial.

5.3.4.2. Treatment of psychosis-like syndromes, epilepsy, and intellectual disability

For the treatment of psychosis-like syndromes, the Karimojong indicated that they sought help from traditional healers because they believed these illnesses were caused by spirits. However, they also indicated that such illnesses were not curable. They did not seek biomedical care because they thought it was neither a cure nor a suitable treatment for "illness of

spirits”. This result is in keeping with evidence from other African studies (Abbo, 2011; Abbo et al., 2008; Akol et al., 2018; Musisi et al., 2010; Okello & Musisi, 2006; Patel et al., 2007; Pringle, 2019; Sorsdahl et al., 2010) regarding the use of traditional healers to treat psychosis.

In the literature, there is wide recognition that indigenous healing or traditional therapies are important resources in global mental health. This recognition is based on the relatively effective care that such therapies are deemed to offer for people with mental health problems (Kirmayer & Swartz, 2014; Pringle, 2019). In SSA, where a lack of resources continues to cripple the bio-medical health systems’ capacity to deliver mental healthcare to the affected populations, traditional healers are an important resource (Jacob et al., 2007; Patel, 2011; Saraceno et al., 2007; WHO, 2002). My results show that the Karimojong relied on indigenous therapy as their main strategy to deal with ill health. Explicitly, indigenous healing was almost exclusively used to treat people with severe mental illness. In addition, many Karimojong depended on indigenous healing for their PHC, including treatment of infectious illnesses like malaria. This finding resonates with Kleinman’s work that explores the nature of healthcare systems in East Asia, and particularly China (Kleinman, 1980).

Building on his analysis that the healthcare of every society reflects its local cultural system in terms of origin, structure, function, and significance, Kleinman shows that the Chinese health system comprises more than medical professionals. It is built on “mutually overlapping relationships among three sectors: the popular, professional and folk sectors” (Kleinman, 1980, pp. 24–35). With specific reference to the folk sector, Kleinman points out that it consists of sacred and secular indigenous healers. The healers serve as a point of last resort for people seeking to have illness interpreted and treated. When people with a mental illness fail to get help from the bio-medical/professional sectors, that is when they and families turn to the folk sector. Usually, the people who come to see healers present with illnesses that are not only explained in terms of misfortune and supernatural aetiology but also require holistic care. Thus, the healers provide services that address all aspects of the sufferer’s life, including, religious, spiritual, and sociomoral needs. In this regard, Kleinman argues that even when sufferers may not get cured, they derive social, emotional and psychological health from this sector (Kleinman, 1980).

The Karimojong articulated related experiences which confirmed how families with relatives suffering from “illness of spirits” took them to the *ngimurok* (traditional healers) to be treated. In this context, treatment for adults with psychosis and children with *ngibangibangi* (“intellectual disability”) was exclusively sought from the *ngimurok* (traditional healers). However, one of the primary concerns of the affected families was to understand the meaning and make sense of their relatives’ suffering. Thus, in their quest for therapy, the families did specific things to deal with mental illness. These included going to consult and ask *ngimurok* (traditional healers) to divine the cause of illness. In this respect, it can be noted that the search for therapy for sufferers started as their families sought to establish the meaning and significance of illness – what was at stake for the afflicted and their relatives (cf. Kleinman, 1980; Kleinman & Becker, 2000). The healers engaged in diagnosis, interpretation, and explanation of the cultural meanings of affliction. They also prescribed and administered therapies for specific illnesses. For instance, for people with spirit possession, the healers performed healing rituals that aimed at initiating them into healing roles.

As can be seen, the interrelated healing roles of the *ngimurok* (traditional healers) seemed to shape the local notions of psychosis and the categorisation of its experience, including desirable treatments. Yet, one may argue that by offering explanations about why sufferers were afflicted and what this meant for them in terms of having social relationships with other people, the healers enabled sufferers and their relations to alleviate suffering (cf. Kleinman & Becker, 2000). As Kleinman and Becker have further pointed out, giving meaning to illness is critical to patients and their families in order to cope with the uncertainties of suffering (Kleinman & Becker, 2000).

Cultural beliefs and structural barriers to the use of bio-medicine tend to inspire people to turn to traditional therapies for both mental and physical health problems (Abbo et al., 2008; Patel et al., 2007). Abbo and colleagues found that many people in Busoga in eastern Uganda relied on traditional healing to treat psychiatric illnesses (Abbo et al., 2008). The reason for this is that the healers were seen as specialists who managed a range of mental health problems. These included psychosis, major depression, anxiety and suicidality. The Busoga frequently sought traditional healing to treat psychosis more often than other mental conditions because psychosis was attributed to supernatural aetiology, and it was believed to only respond to indigenous therapy (Abbo et al., 2008).

The finding that bio-medical care was not sought because it was thought to be neither a cure nor a suitable treatment for “illness spirits” speaks to the broader challenges of the bio-medical system (Gray, 2010; Sundal, 2012). These studies have shown that structural inequalities combined with the erratic nature of the available bio-medical healthcare services negatively impact the local people’s strategies used to cope with poor health, especially maternal and child health. The studies also show that the structure of bio-medical services presents further impediment to the efficacy of especially mother’s interventions on behalf of their children’s health. In this regard, mothers are forced to seek alternative therapies. In particular, women seek the services of traditional healers because they are perceived to be more individualised, culturally meaningful, and empathetic treatments (cf. Gray, 2010).

Elsewhere, research has also shown that people in low-resource settings often have recourse to traditional healing because it addresses their needs in a holistic way. Moreover, in most African cultures people tend to have cultural and emotional attachment to their local healing systems (Pringle, 2019). In this context, traditional healers are said to be easily acceptable to the communities they serve because they are readily available. More importantly, they share culturally based explanations of (mental) illness and understandings of illness behaviour with the local communities (Becker & Kleinman, 2014). It would seem that the Karimojong embraced this kind of rationality as well. As we saw, for example, whereas indigenous healers were in some instances said not to offer the best remedies for “illness of spirits”, such remedies were still utilised. Moreover, the families affected by the experience of “illness of spirits” contextually situated and negotiated their help-seeking decisions and actions. That is, their therapeutic decisions and actions were based on local understandings of the structural dynamics that shaped (mental) illness and health in the Karimojong society (cf. Good, 1997). Thus, it seems that the Karimojong took pragmatic steps to use available mental health resources, and in particular, traditional healing because it at least gave them proximate success; the realisation of hopeful culture-specific indications that a given therapy has a desired effect (Etkin, 1988, cited in Rubel & Hass, 1996, p. 127).

However, the results further show that the Karimojong sought care for children with epilepsy from the bio-medical health system, despite its weaknesses discussed above. This is a key finding that highlights the fact that the Karimojong are medically pluralistic, that is, they dynamically use both bio-medical and indigenous resources to treat illness (Rasmussen,

2008; Sundal, 2012). And evidence shows that the medical pluralism is beneficial in the sense that it can facilitate better illness diagnosis, interpretation, and healing (Helman, 1994; Kleinman, 1980). But the research found that the bio-medical treatments for epilepsy were only used by those families living in close proximity to Moroto hospital. So, it is possible that they accessed services because they were aware of the availability of pharmacological antiepileptic drugs in the hospital. Indeed, during my observations of health-seeking behaviour at this bio-medical facility, I found that antiepileptic drugs were prescribed and dispensed for some children diagnosed with seizure attacks. It is also possible families of children with epilepsy decided to use bio-medicine as one of the ways that would enable them to cope with the significant stigma and care burden posed by the illness. Studies have found that the burden of caring for people with epilepsy is particularly daunting especially if people have no access to effective cures (Duggan, 2013). However, the access and use of bio-medicine to treat epilepsy is important evidence, suggesting that if psychotropic treatments, and particularly antiepileptic drugs, were to be made available, the Karimojong could utilise them to treat afflicted people. In addition, if the Karimojong realised positive effects from the utilisation of antiepileptic drugs, then most likely this would enhance adherence to such treatments (cf. Ventevogel et al., 2013).

More importantly, the Karimojong's tendency to engage in pluralistic health-seeking behaviours when faced with troubling illness experiences such as epilepsy, underlines the potential for collaboration between indigenous and bio-medical mental healthcare systems. This is particularly important given that indigenous healers appear to make a substantial contribution to meeting the health needs of the Karimojong and of people living in other parts of Uganda (Abbo, 2011). Moreover, their healing roles also appeared to fill a critical healthcare gap for the different physical illnesses among the Karimojong where the bio-medical system is reported to be erratic and is faced with numerous structural inequities (Gray, 2010).

The need for collaborative efforts among indigenous and bio-medical systems has been documented and widely discussed in several studies (Akol et al., 2018; Abbo, 2011; Pringle, 2019). A consistent opinion is that tapping into the relative competencies of each of these systems can lead to the delivery of effective mental healthcare to the affected populations. Specifically, it is argued that embracing a collaborative model can greatly improve access to

care and promote the mental health well-being of patients, particularly in SSA where a huge treatment gap persists but skilled bio-medical human resources are extremely scarce and poorly distributed.

While indigenous healers seem to be an important part of the mental healthcare system in low-resource settings such as Uganda (Akol, 2018; Abbo, 2011), their interaction with the bio-medical system has often been made difficult due to several obstacles. The greatest obstacle to getting the two medical systems to work together is the mutual suspicion between them and the concerns of the bio-medical and the religious sectors regarding the “unscientific” and unorthodox practices of traditional healers (Abbo, 2011; Patel, 2011). A more recent study exploring collaborative efforts between bio-medical and non-bio-medical systems in Ghana (Kpobi & Swartz, 2019) reiterates how mistrust hinders integration of the two systems. Kpobi and Swartz (2019) indicate that while traditional and bio-medical systems have succeeded in building primary health partnerships, collaboration in mental healthcare has remained largely unsuccessful. The key reason for this is the failure to reconcile competing explanatory models of mental illness held by the traditional healers and bio-medical providers. That is, strong disagreements exist regarding what constitutes illness, and this suggests competition for power and legitimacy between the two medical systems (Kpobi & Swartz, 2019). The authors thus argue that a recognition of such differences is essential if integration of the two systems of care is to be realised (Kpobi & Swartz, 2019). This resonates with the view that for collaboration between traditional and bio-medical systems to succeed, there is a need to see their different therapies as not necessarily competitive but complementary (Patel, 2011).

In this section, I have examined the question of treatment of mental illness in Karamoja. The results highlight that the Karimojong primarily relied on the use of traditional healthcare to manage mental health issues, but to some extent bio-medical care was also used, particularly to treat epilepsy. In the next chapter, I present the conclusions, and describe the implications for intervention and research.

Chapter Six

Conclusion

6.1. Introduction

In this chapter, I discuss the implications of this study for intervention and practice to improve mental health in Karamoja. In addition, I suggest directions for future research and outline the limitations of this research.

6.2. Conclusions

This research examined cultural understandings of mental illness among nomadic pastoralists living in a context of severe humanitarian crisis in Karamoja, Uganda. It was assumed that while culture shapes lay EMs of mental illness, these are also shaped by contextual factors such as poverty, violence and marginalisation. It was also assumed that a clear grasp of context is vital for better understanding of how lay EMs and related behaviours are informed by culture. In other words, the lay EMs of mental illness are shaped not only by culture, but also by context. Considering the results described and discussed above I can draw the following conclusions.

The Karimojong articulated cultural understandings of mental illness in complex but meaningful ways. The cultural concepts of mental illness described referred to different local syndromes, some of which map onto the psychiatric constructs, but others differ significantly. The specific cultural syndromes described were categorised in relation to psychosis, depression, psychological trauma, epilepsy, and intellectual disability.

Psychosis was seen as a complex and multilayered illness comprising three distinct subtypes, namely *ngikerep*, *ngimathimathi*, and *ngiwai wai*. And each of these subtypes of psychosis had a cultural-specific meaning that was not only linked to specific illness beliefs, but also to other aspects of the Karimojong society. For instance, people with *ngiwai wai* lacked the capacity to use cultural symbols and thus were thought to lack vigilance. Yet vigilance was critical for survival in the Karamoja context of everyday armed violence and insecurity.

The local syndrome, defined as having many thoughts, sadness, worries, and solitude, are core features resembling major depression, but was not seen as a persistent problem and thus

was not treated. The local syndrome that resembled psychological trauma was perceived to symbolise widespread and collective suffering. In addition, the local syndromes of epilepsy and intellectual disability were identified but were considered to be childhood mental illnesses.

The Karimojong held multiple explanatory models for the different local syndromes. However, the models significantly reflected supernatural and psychosocial explanations of mental illness and less so biological explanations. Psychosis-like syndromes were seen as illnesses caused by the actions of different supernatural agents: God, ancestor spirits, the spirits of dead people/ghosts, curses, and bewitchment. The causes of depressive illness and psychological trauma were considered to be social and contextual factors. Experiences of epilepsy and intellectual disability were believed to be largely supernatural in nature, being similar to the explanations of psychosis. However, epilepsy and intellectual disability were regarded as having a biological aetiology, with mainly genetic and physical factors.

Because psychosis, epilepsy, and intellectual disability were seen to be magico-spiritual conditions and not curable, the sufferers and their families confronted numerous health and social challenges. They were exposed to negative societal attitudes such as the belief that sufferers were violent and dangerous people. Moreover, the Karimojong also held fearful beliefs that epilepsy was contagious. Such beliefs seem to reflect low level mental health literacy (Jorm et al., 1997), and may subject sufferers to certain forms of human rights abuse. More importantly, such fearful beliefs appeared to significantly contribute to stigmatisation and discrimination of the sufferers and their families. For instance, not only were afflicted people excluded from participating in social activities, but their families were stigmatised as being punished for immoral conduct. Other people refused to marry into families with a history of severe mental illness, just as people with psychosis faced the challenge of failure to marry.

In terms of treatment, the results revealed that the Karimojong primarily relied on the services of traditional care providers to treat people with psychosis as well as epilepsy and intellectual disability. Although the Karimojong sought treatment for mental illness from the traditional healers, they were not considered to offer effective cures. This confirms the results of previous Africa-based research (Abbo et al., 2008; Kpobi & Swartz, 2018; Sorsdahl et al.,

2010) which has found that they play an important role in mental healthcare. In addition, these studies have also demonstrated that people living in resource-scarce contexts tend to engage in pragmatic actions to utilise local resources, particularly traditional healers, to treat mental illness for two major reasons. First, they are usually deemed to provide culturally suitable therapy for illness thought to be caused by spiritual and social agents. Second, because indigenous healers are often part of the local communities, they are easily accessible and trusted. These views are supported by the current results as well.

For the treatment of epilepsy, the results found that the Karimojong engaged in medical pluralism (Rasmussen, 2008). This means that they also made use of all available healing systems, including bio-medicine, to treat epilepsy. This tendency to engage in pluralistic health-seeking behaviours by the Karimojong can provide opportunities for collaboration between the bio-medical care system and traditional healers. Thus, the results support the call for getting the indigenous healers and bio-medical care providers to work together in order to deliver mental healthcare needed by affected people (Abbo, 2011; Kirmayer & Swartz, 2014; Kpobi & Swartz, 2018). Embracing a collaborative model can greatly improve access to care and promote the mental health well-being of patients, particularly in SSA where a huge treatment gap persists but skilled bio-medical human resources are extremely scarce and poorly distributed.

However, there is a need to address the issue of mutual suspicion and mistrust (Kpobi & Swartz, 2019; Patel, 2011), which has been found to hamper integration of the two systems. Such mutual suspicion and mistrust has largely been grounded in the failure to reconcile competing explanatory models of mental illness held by the traditional healers and bio-medical providers. For instance, strong disagreements exist between the two medical systems regarding what constitutes illness, which also highlights competition for power and legitimacy between them. Therefore, there is a need for recognition of such differences if integration of the two systems of care is to be realised (Kpobi & Swartz, 2019). Indeed, in the Karamoja context where the bio-medical system is confronted with numerous functional problems (Gray, 2010), this possibility needs to be seriously explored. But for collaboration between two medical systems to succeed, there is a need to see their different therapies as not necessarily competitive but complementary (Patel, 2011).

6.3. Implications of this study

The study has a number of significant implications for public health intervention and practice, and mental health research, in Karamoja, and Uganda in general.

6.3.1. Implications for intervention and practice

The idea that psychosis is a complex and multilayered illness may pose serious challenges in terms of its diagnosis and treatment. Mental health professionals such as psychiatrists need to have a clear understanding of how cultural and contextual dynamics shape the experience and interpretation of mental health issues in Karamoja. This understanding is important because it can inform the design of culturally sensitive interventions, enabling psychiatrists and other bio-medically trained therapists, including clinical psychologists, to appropriately address the mental health needs of the Karimojong.

Given the overlaps in the beliefs about conceptualisations of mental health issues, particularly with regard to the local syndromes of depression and psychological trauma, a useful and flexible strategy to manage such issues may be the common elements treatment approach (CETA) (Bolton et al., 2014; Murray et al., 2013). This approach has been found to be effective in improving mental health outcomes in other low-income settings such as Iraq and Burma. In these settings, therapists using the CETA have been able to shift focus from simply dealing with a single diagnostic category like psychosis to managing different mental health problems by applying transdiagnostic intervention. In the Karamoja context of multiple structural and environmental stressors, CETA can enable mental health providers to effectively diagnose and treat those cultural syndromes that closely resemble depression and psychological trauma. Besides offering holistic intervention, CETA would deliver cost-effective evidence based treatments (EBTs) (Bolton et al., 2014; cf. Lund et al., 2018; Murray et al., 2013).

In the case of the local syndrome *akiyalolong* (“depressive illness”), this was not just a random condition caused by natural factors, but rather it was linked to undesirable social circumstances such as immense loss of livestock and deprivation. As a result, it was not regarded as a medical condition in need of treatment, but rather a social problem requiring social solutions. Such solutions involved receiving social and emotional support from relatives and friends. This shows how understandings of mental health cannot be divorced

from context. In this context, a psychiatrist working with the bio-medical definition of depression is likely to be less successful in Karamoja. Given the widespread social suffering (Kleinman, 2000) caused by violence and deprivation in Karamoja, and where depression is seen as an utterly normal response to such conditions, use of psychiatric strategies to address depression might instead medicalise everyday life distress (Boyle, 2013; Summerfield, 2008).

The Karimojong strong belief in supernatural and psychosocial explanations of mental illness seems to support the hypothesis of limited awareness of bio-medical models of mental illness in SSA (Patel et al., 2007). However, ascription of mental illness to spiritual factors also spoke to other important social aspects of their society. For example, the spiritual explanations of *ngilam* (curses) and *akisub l'thuam* (bewitchment) also expressed issues of social tensions and conflicts, gender inequality, and access to power, amongst others. This implies that mental health interventions must also address structural problems in order to be effective. For example, management of psychosis would involve provision of psychotropic treatments in combination with community-based mental healthcare and out-reach services such as psychosocial support.

Given that traditional healers appeared to be a valuable source of care for both mental and physical health problems, it is important that their role in (mental) healthcare be properly acknowledged and understood. Similarly, given that difficult access significantly undermined the Karimojong's efforts to utilise bio-medicine, the health system needs to be reformed with a view of improving (mental) health services. Consequently, the bio-medical health system will need to work together with traditional healers to provide mental healthcare to those who need it. Such an integrated approach would ensure appropriate use of all available resources with a view of improving people's access to quality mental healthcare (Abbo et al., 2008; cf. Swartz, 1998). Moreover, developing a healthcare system based on an integrated approach could allow psychiatric professionals to effectively manage mental health needs of the population for which they have requisite expertise, on the one hand. On the other hand, this would ensure that traditional healers continue to deliver care that enables the people to understand and manage their mental illness experience within a meaningful worldview (cf. Teuton et al., 2007). In this regard, the few mental health specialists that do exist together with traditional healers could complement each other and work together to offer the best they can for the users of available mental healthcare (Patel, 2011).

Furthermore, evidence demonstrates that global efforts that seek to address the mental health needs of populations living in low resource settings, including those affected by humanitarian crises tend to be ineffective due to what has been termed as a credibility gap. The credibility gap refers to a mismatch between health specialists' explanatory models of mental illness and those held by the local people (Patel, 2014b). Such a mismatch, not only results in the failure by mental health interventions to significantly reduce the treatment gap for people with mental illness but also an inability to improve mental health for whole populations. In order to reduce this mismatch, Patel (2014b) argues that there is a need to use different innovative models of care, including integrating culturally appropriate EMs in mental healthcare interventions. Given that the Karimojong engage in medical pluralism partly due to a dysfunctional bio-medical system, integrating mental health services may help to improve access to care for mental illness as well as address social and economic needs (Patel, 2011, 2014b). As Patel (2014b) further argues, a policy that fosters integration of culturally appropriate EMs in mental health services can be helpful in addressing the demand side barriers of mental healthcare. That is, barriers related to immensely different understandings of mental illness held by the local communities. This in turn can expand access to mental healthcare interventions and improve their efficacy, especially in low resource settings.

Structural factors that include extreme poverty, famine, and poor health infrastructure are indicative of the long term impact of the active political marginalisation and socio-economic isolation of the Karimojong by the state. Therefore, there is need for the state to end marginalisation and isolation in order to meaningfully promote the human rights or entitlements of the Karimojong (Sen, 1999). Solutions are as much political and social as they are about the diagnosis and treatment of mental illness.

- End violence and insecurity, which are part of the major structural problems that make access to the bio-medical system difficult.
- Improve access to safe water and sanitation facilities. Lack of access to such facilities tends to expose people to frequent outbreaks of preventable physical diseases and yet the comorbidity between such illness and mental illness is well established.
- To alleviate poverty and improve livelihoods by providing and expanding the social protection grant and ensure transfer cash to all vulnerable people in Karamoja such that they are able to access basic needs: food, housing, clothing and healthcare.

6.3.2. Implications for future research

- Future research could explore the epidemiology of mental illness so as to provide insights that can inform the development of preventive intervention strategies.
- Future research should increase the knowledge base about the structure and functioning of the indigenous medical system in relation to mental healthcare.
- Further research is required to better understand the local strategies of coping with common mental disorders such as depression and psychological trauma among the Karimojong.

6.4. Study limitations

The study used multiple qualitative research techniques that limited the focus on specific lines of inquiry. In this regard, the study was unable to capture epidemiological data on the burden of mental illness. Specifically, the lack of quantitative data limited my analysis with regard to understanding the incidence and prevalence rates of mental illness in this population. In addition, the data for this study were largely based on understanding the global concept of mental illness and perceptions of the non-afflicted about people with mental illness. In this context, the study relied on “experience-near” (Geertz, 1974) where the views of non-afflicted people were used to define what they saw, felt, thought, and understood as mental illness in their community. Thus, I did not explore the perspectives of afflicted people and what they directly experienced as mental illness. The use of such a phenomenological approach would have enriched the data by understanding mental illness as a subjective and everyday experience of people with mental illness. Moreover, this would have enabled me to stay as close as possible to the meanings of what afflicted people themselves understood as mental illness in everyday terms. Another potential limitation of this study may be interviewer bias related to my role as a researcher – an “outsider” – studying a culture different from mine. However, I engaged in constant self-reflection and positioned myself in ways that enabled me to exchange roles with participants; they were facilitators and I was a learner. In doing so, I was able to contextualise and interpret participants’ views about mental illness. More importantly, I also tried to reduce the possibility of interviewer bias by working with local bicultural and bilingual (one male and two female) research assistants. Thus, I trust that my findings reflect the cultural knowledge and practices of the Karimojong.

Finally, the current validity of the data may be called into question given the lapse of time between fieldwork and presentation of the thesis. This was because of unforeseen delays in administrative clearance by Stellenbosch university. However, in terms current validity of the research, recent studies of conflict sensitivity (RoU, 2015) and human capacity development indices (UBOS, 2016, 2017; UNFPA, 2018) in Karamoja have reported findings that lend support to my data. The conflict sensitivity analysis (RoU, 2015) reveals although there is relative peace and stability following the forceful military-led disarmament, security remains fragile in Karamoja. This is mainly attributed to new threats to security caused by armed cattle rustlers from within the local communities and across the border from Kenya and Southern Sudan. In the case of human capacity development, Karamoja continues to have the worst indicators of well-being compared to the rest of Uganda. The region is characterised by a remote and ecologically hostile context and the people face continued socio-politico-economic marginalisation (UBOS, 2016, 2017; UNFPA, 2018). Consequently, there are multiple development challenges, which include persistent food and water shortages, chronic poverty, poor infrastructure, high prevalence of preventable diseases, and poor literacy and skills development (UBOS, 2017). This clearly suggests that there have no significant shifts in the cultural life and social conditions of the Karimojong over the last decade. In this respect, the evidence documented above further augments the validity of my data.

In spite of the above limitations, the study is of major public health significance. It is the first of its kind to make an important contribution to understandings of mental health issues among nomadic pastoralists in Uganda. The study provides a rich contextual image of the Karimojong, revealing a complex cultural system with sophisticated coping strategies that enable them to survive in a distressed context. In particular, it reveals how one of the world's poorest and most marginalised populations articulates issues regarding (mental) health and well-being. This study is therefore not only of mental health relevance, but it also helps to unearth the broader socio-economic and political issues that impact well-being in Karamoja. Consequently, it provides new insights that can inform the design of culturally sensitive and suitable mental health interventions for the Karimojong and similar populations in Uganda.

References

- Abbo, C. (2011). Profiles and outcome of traditional healing practices for severe mental illnesses in two districts of Eastern Uganda. *Global Health Action*, 4: 7117 - DOI: 10.3402/gha.v4i0.7117.
- Abbo, C., Ekbal, S., Waako, P., Okello, E., & Musisi, S. (2009). The prevalence and severity of mental illnesses handled by traditional healers in two districts in Uganda. *African Health Sciences*, 9(1), S16–S22.
- Abbo, C., Okello, E., Ekblad, S., Waako, P., & Musisi, S. (2008). Lay concepts of psychosis in Busoga, Eastern Uganda: A pilot study. *WCPRR*, 132–145.
- Adewuya, A. O., & Makanjuola, R. O. (2008). Lay beliefs regarding causes of mental illness in Nigeria: pattern and correlates. *Social Psychiatry and Psychiatric Epidemiology*, 43, 336–341.
- Adjei, P., Akpalu, A., Laryea, R., Nkromah, K., Sottie, C., Ohene, S., & Osei, A. (2013). Beliefs on epilepsy in Northern Ghana. *Epilepsy & Behavior*, 29, 316–321.
- Adriaens, P. R., & De Block, A. (2013). Why we essentialize mental disorders. *Journal of Medicine and Philosophy*, 38, 107–127. doi:10.1093/jmp/jht008
- Agabi, C. E., & Wilson, J. P. (2005). Trauma, PTSD, and resilience: A review of literature. *Trauma, Violence, & Abuse*, 6(3), 195–216. doi:10.1177/1524838005277438.
- Akello, G., Richters, A., & Ovuga, E. (2010). Children's management of complaints symptomatic of psychological distress: A critical analysis of the different approaches in Northern Uganda. *African Journal of Traumatic Stress*, 1(2), 70–79.
- Akol, A., Moland, K. M., Babirye, J. N., & Engebretsen, I. M. S. (2018). "We are like co-wives": Traditional healers' views on collaborating with the formal Child and Adolescent Mental Health System in Uganda. *BMC Health Services Research*, 18:258. doi.org/10.1186/s12913-018-3063-4.
- Allotey, P., & Reidpath, D. (2007). Epilepsy, Culture, Identity and Well-being: a study of the social, cultural and environmental context of epilepsy in Cameroon. *Journal of Health Psychology*, 12(3): 431-443. DOI: 10.1177/1359105307076231.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Anderson, K. K., Fuhrer, R., & Malla, A. K. (2010). The pathways to mental healthcare of first-episode psychosis patients: a systematic review. *Psychological Medicine*, 40, 1585–1597. doi:10.1017/S0033291710000371

- Angermeyer, M. C., & Dietrich, S. (2006). Public beliefs about and attitudes towards people with mental illness: a review of population studies. *Acta Psychiatrica Scandinavica*, 113, 163–179.
- Attride-Stirling, J. (2001). Thematic networks: an analysis tool for qualitative research. *Qualitative Research*, 1(3), 385–405.
- Audet, C.M., Ngobeni, S., Graves, E. & Wagner, R. G. (2017). Mixed methods inquiry into traditional healers' treatment of mental, neurological and substance abuse disorders in rural South Africa. *PLoS ONE*, 12(12): e0188433. doi.org/10.1371/journal.pone.0188433.
- Audi, R. (2003). *Epistemology: A contemporary introduction to the theory of knowledge*. New York: Routledge.
- Avoke, M. (2002). Models of disability in the labelling and attitudinal discourse in Ghana. *Disability & Society*, 17(7), 769–777. doi:10.1080/0968759022000039064
- Banner, N. F. (2013). Mental disorders are not brain disorders. *Journal of Evaluation in Clinical Practice*, 19, 509–513.
- Barber, J. P. (1962). The Karamoja district of Uganda: A pastoral people under colonial rule. *The Journal of African History*, 3(1), 111–124.
- Becker, A. E., & Kleinman, A. (2013). Global health: Mental health and the global agenda. *The New England Journal of Medicine*, 369, 66–73. doi:10.1056/NEJMr1110827.
- Becker, A. E., & Kleinman, A. (2014). The history of cultural anthropology in the last half-century. In S. Bloch, S. A. Green, & J. Holmes, *Psychiatry: Past, present, and prospects* (pp. 74–95). Oxford: Oxford University Press.
- Bedirhan, T. U. (1999). The global burden of mental disorders. *American Journal of Public Health*, 89, 1315–1318.
- Belfer, M. L. & Samarasan, D. (2012). Missing voices: Speaking up for the rights of children and adolescents with disabilities. In M. Dudley, D. Silove, & F. Gale (Eds.), *Mental health and human rights: vision, praxis and courage* (pp. 476–482). Oxford: Oxford University Press.
- Belfer, M. L., & Saxena, S. (2006). WHO child atlas. Lancet Series 367.
- Bentz, V. M., & Shapiro, J. J. (1988). *Mindful inquiry in social research*. London: SAGE Publications.
- Berg, B. L. (2001). *Qualitative research methods for the social sciences*. Boston: Allyn and Bacon.

- Bernard, H. R., & Ryan, G. W. (1998). Text analysis: Qualitative and quantitative methods. In H. R. Bernard, *Handbook of methods in cultural anthropology* (pp. 595–646). Walnut Creek: AltaMira Press.
- Berry, J. W., Poortinga, Y. H., Segall, M. H., & Dasen, P. R. (2002). *Cross-cultural psychology: Research and applications*. Cambridge: Cambridge University Press.
- Betancourt, T. S., Speelman, L., Onyango, G., & Bolton, P. (2009). A qualitative study of mental health problems among children displaced by war in northern Uganda. *Transcultural Psychiatry*, 46(2), 238–256. doi:10.1177/1363461509105815.
- Bevan, J. (2008). *Crisis in Karamoja : Armed violence and the failure of disarmament in Uganda's most deprived region. Occasional paper 21*. Geneva: Graduate Institute of International and Development Studies.
- Beyero, T., Alem, A., Kebede, D., Shibre, T., Desta, M., & Deyessa, N. (2004). Mental disorders among the Borana semi-nomadic community of Southern Ethiopia. Research Report. *World Psychiatry*, 3(2), 110–114.
- Bhana, A. (2010). Middle childhood and pre-adolescence. In I. Peterson, A. Bhana, A. J. Flisher, L. Swartz, & L. Richer, *Promoting mental health in scarce-resource contexts: Emerging evidence and practice* (pp. 124–142). Cape Town: HSRC Press.
- Bhugra, D., & Mastrogianni, A. (2004). Globalisation and mental disorders : Overview with relation to depression. *British Journal of Psychiatry*, 184, 10–20.
- Bhugra, D., Till, A., & Sartorius, N. (2013). What is mental health? *International Journal of Social Psychiatry*, 59(1), 3–4. doi:10.1177/0020764012463315
- Bhui, K., & Bhugra, D. (2002). Explanatory Models for mental distress : implications for clinical practice and research. *British Journal of Psychiatry*, 181, 6–7.
- Bigby, C., & Frawley, P. (2010). *Social work practice and intellectual disability*. Basingstoke: Palgrave Macmillan.
- Bock, P. K. (1999). *Rethinking psychological anthropology: Continuity and change in the study of human action* (2nd ed.). Long Grove: Waveland Press, Inc.
- Bolton, P., Bass, J., Betancourt, T., Speelman, L., Onyango, G., Clougherty, K. F., . . . Verdelli, H. (2007). Interventions for depression symptoms among adolescent survivors of war and displacement in Northern Uganda: A randomised controlled trial. *JAMA*, 298(5), 519–527. doi:10.1007/s00127-008-0475-1.
- Bolton, P., Bass, J., Neugebauer, R., Verdelli, H., Clougherty, K. F., Wickramaratne, P., . . . Weissman, M. (2003). Group interpersonal psychotherapy for depression in rural

- Uganda: A randomised controlled trial. *JAMA*, 289(23), 3117–3124.
doi:10.1001/jama.289.23.3117
- Bolton, P., Lee, C., Haroz, E. E., Murray, L., Dorsey, S., Robinson, C., . . . Bass, J. (2014). A transdiagnostic community-based mental health treatment for comorbid disorders: Development and outcomes of a randomised controlled trial among Burmese refugees in Thailand. *PLOS Medicine*, 11(11), e1001757. doi:10.1371/journal.pmed.1001757
- Boyle, M. (2013). The persistence of medicalisation: Is the presentation of alternatives part of the problem? In S. Coles, S. Keenan, & B. Diamond, *Madness contested: Power and practice* (pp. 4–22). Ross-on-Wye: PCCS Books.
- Bradley, E. H., Curry, L. A. & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research*, 42(4), 1758–1772.
- Braun, V. & Clark, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2): 77-101.
- Breslau, J., Miller, E., Jin, R., & Sampson, N. A. (2011). A multinational study of mental disorders, marriage, and divorce. [HYPERLINK "https://www.ncbi.nlm.nih.gov/entrez/eutils/efetch.fcgi?dbfrom=pubmed&retmode=ref&cmd=prlinks&id=21534936"](https://www.ncbi.nlm.nih.gov/entrez/eutils/efetch.fcgi?dbfrom=pubmed&retmode=ref&cmd=prlinks&id=21534936) \t "pmc_ext" *Acta Psychiatrica Scandinavica*, 124(6), 474–486. doi: [HYPERLINK "https://dx.doi.org/10.1111/j.1600-0447.2011.01712.x"](https://dx.doi.org/10.1111/j.1600-0447.2011.01712.x) \t "pmc_ext" 10.1111/j.1600-0447.2011.01712.x
- Brettell, C. B. (1998). Fieldwork in the archives: Methods and sources in historical anthropology. In H. R. Bernard, *Handbook of methods in cultural anthropology* (pp. 513–546). Walnut Creek: AltaMira Press.
- Brolan, C. E., van Dooren, K., Gomez, M. T., Fitzgerald, L., Ware, R. S., & Lennox, N. G. (2014). Suranho healing: Filipino concepts of intellectual disability and treatment choices in Negros Occidental. *Disability & Society*, 29(1), 71–85.
doi:10.1080/09687599.2013.771899
- Bury, M. (1991). The sociology of chronic illness: a review of research prospects. *Sociology of Health & Illness*, 13(4), 451–468.
- Callard, F., Sartorius, N., Arboleda-Florez, J., Bartlett, P., Helmchen, H., Stuart, H., . . . Thornicroft, G. (2011). *Mental Illness, Discrimination and the law: Fighting for social justice*. Oxford: Wiley-Blackwell.

- Carod-Artal, F. J., & Vázquez-Cabrera, C. B. (2007). An anthropological study about epilepsy in native tribes from Central and South America. *Epilepsia*, 48(5), 886–893. doi:10.1111/j.1528-1167.2007.01016.x
- Castillo, R. J. (1997). *Culture & mental illness: A client-centered approach*. Pacific Grove, California: Brooks/Cole Publishing Company.
- Chandra, P. S., Kommu, J. V., & Rudhran, V. (2012). Schizophrenia in women and children: A selective review of literature from developing countries. *International Review of Psychiatry*, 24(5), 467–482.
- Chisholm, D., Flisher, A. J., Lund, C., Patel, V., Saxena, S., Thornicroft, G., & Tomlinson, M. (2007). Scale up services for mental disorders: a call for action. *Lancet*, 370(9594), 1241–1252. doi:10.1016/S0140-6736(07)61242-2.
- Chisholm, D., Sweeny, K., Sheehan, P., Rasmussen, B., Smit, F., Cuijpers, P., & Saxena, S. (2016). Scaling-up treatment of depression and anxiety: a global return on investment analysis. *Lancet Psychiatry*, 3: 415–24. doi.org/10.1016/S2215-0366(16)30024-4.
- Christensen, P. H. (2004). Children’s participation in ethnographic research: issues of power and representation. *Children & Society*, 18, 165–176.
- Christensen, P. H., & James, A. (2000). *Childhood diversity and commonality: some methodological insights*. London/New York: Falmer Press.
- Cohen, A., Patel, V., & Minas, H. (2014). A brief history of global mental health. In V. Patel, H. Minas, A. Cohen, & M. J. Prince, *Global mental health: Principles and practice* (pp. 3–26). Oxford: Oxford University Press.
- Cook, K. E. (2005). Pearls, pith, and provocation: Using critical ethnography to explore issues in health promotion. *Qualitative Health Research*, 15, 129–138.
- Crotty, M. (1998). *The foundations of social research: meaning and perspective in the research process*. London/Thousand Oaks/New Delhi: SAGE Publications.
- Czuba, K. (2011). *Governing the Karimojong: Tradition, modernity and power in contemporary Karamoja*. Kampala: BRAC Research and Evaluation Unit.
- Dancause, K. N., Akol, H. A., & Gray, S. J. (2010). Beer is the cattle of women: Sorghum beer commercialization and dietary intake of agropastoral families in Karamoja, Uganda. *Social Science & Medicine*, 70, 1123–1130.
- Daniels, K., Van Zyl, H. H., Clarke, M., Dick, J., & Johansson, E. (2005). Ear to the ground: listening to farm dwellers talk about the experience of becoming lay health workers. *Health Policy*, 73, 92–103.

- Davies, C. A. (1999). *Reflexive Ethnography. A guide to researching selves and others*. London: Routledge.
- Dawson, S., Manderson, L., & Tallo, V. L. (1993). *Methods for social research in disease: A manual for the use of focus group*. Boston: International Nutrition Foundation for Developing Countries (INFDC).
- De Jong, J. T., & Reis, R. (2010). Kiyang-yang, a West-African postwar idiom of distress. *Culture, Medicine and Psychiatry*, 34, 301–321. doi:10.1007/s11013-010-9178-7.
- De Maio, F. (2010). *Health and social theory*. Basingstoke: Palgrave Macmillan.
- Desjarlais, R., Eistenberg, L., Good, B., & Kleinman, A. (1995). *World mental health: problems and priorities in low income countries*. New York: Oxford University Press, Inc.
- Dey, I. (1993). *Qualitative data analysis: A user-friendly guide for social scientists*. London and New York: Routledge.
- Dhanda, A., & Narayan, T. (2007). Mental health and human rights. *Lancet*, 1197–1198. doi:10.1016/S0140-6736(07)61247-1.
- Docrat, S., & Lund, C. (2019). SA's 92% mental health treatment gap. <https://www.news.uct.ac.za/article/-2019-10-10-sas-92-mental-health-treatment-gap>, last accessed 28 June 2020.
- Dodge, C. P. (1986). Uganda—Rehabilitation or redefinition of health services? *Social Science & Medicine*, 22(7), 755–761.
- Dodge, C. P., & Wiebe, P. D. (Eds.). (1985). *Crisis in Uganda: The breakdown of health services*. Oxford: Pergamon Press.
- Dudley, M., Silove, D., & Gale, F. (Eds.). (2012). *Mental health and human rights: vision, praxis and courage*. Oxford: Oxford University Press.
- Duggan, M. B. (2013). Epilepsy and its effects on children and families in rural Uganda. *African Health Sciences*, 13(3), 613– 623. doi:10.4314/ahs. v13i3.14.
- Eaton, J., McCay, L., Semrau, M., Chatterjee, S., Baingana, F., Araya, R., . . . Saxena, S. (2011). Scale up of services for mental health in low-income and middle-income countries. *Lancet*, 378: 1592–603. DOI:10.1016/S01406736(11)60891-X.
- Eaton, W. W., Muntaner, C., & Sapag, J. C. (2010). Socioeconomic stratification and mental disorders. In T. L. Scheid, & T. N. Brown (Eds.), *A handbook for the study of mental health: Social contexts, theories, and systems* (pp. 226–255). Cambridge: Cambridge University Press.

- Edgerton, R. B. (1996). Conceptions of psychosis in four East African societies. *American Anthropology*, 68, 408–425.
- Eriksen, T. H., & Nielsen, F. (2001). *A history of anthropology*. London: Pluto Press.
- Fairburn, C. G., & Patel, V. (2014). The global dissemination of psychological treatments: A road map for research and practice. *American Journal of Psychiatry*, 171(5)
- Fekadu, A., Medhin, G., Lund, C., DeSilva, M., Selamu, M., Alem, A ... Hanlon, C. (2019). The psychosis treatment gap and its consequences in rural Ethiopia. *BMC Psychiatry*, 19:325. doi.org/10.1186/s12888-019-2281-6.
- Fernandes, P. T., Snape, D. A., Beran, R. G., & Jacoby, A. (2011). Epilepsy stigma: What do we know and where next? *Epilepsy & Behavior*, 22, 55–62.
- Fisher, J., Herrman, H., Cabral de Mello, M., & Chandra, P. S. (2014). Women's mental health. In V. Patel., H. Minas., A. Cohen, & M. J. Prince (Eds.), *Global mental health: Principles and practice* (pp. 354–383). Oxford: Oxford University Press.
- Forbes, M.K., Crome, E., Sunderland, M., & Wuthrich, V, M. (2017). Perceived needs for mental health care and barriers to treatment across age groups. *Aging & mental health*, 21 (10): 1072 -1078. dx.doi.org/10.1080/13607863.2016.1193121.
- Foucault, M. (1987). *Mental illness and psychology*. Berkeley: University of California Press.
- Fratkin, E. (2004). *Ariaal pastoralists of Northern Kenya*. Needham Heights, MA: Allyn and Bacon.
- Fratkin, E. (2014). Ethiopia's pastoralist policies: Development, displacement and Resettlement. *Nomadic Peoples*, 18, 94–114. doi:10.3197/np.2014.1801107.
- Fratkin, E., & Meir, A. (2005). Pastoralists and the state: An editorial introduction. *Geography Research Forum*, 25, 1–13.
- Fratkin, E., Roth, E. A., & Nathan, M. A. (2004). Pastoral sedentarisation and its effects on children's diet, health and growth among Rendille of northern Kenya. *Human Ecology*, 32(5), 531–559.
- Geertz, C. (1973). *The interpretation of cultures*. New York: Basic.
- Geertz, C. (1974). "From the Native's point of view", On the nature of anthropological understanding. *Bulletin of the American Academy of Arts and Sciences*, 28(1), 26–45.
- Golightley, M. (2008). *Social work and mental health* (3rd ed.). Exeter: Learning Matters Ltd.
- Good, B. J. (1977). The heart of what's the matter. The semantics of illness in Iran. *Culture, Medicine and Psychiatry*, 1, 25–58.

- Good, B. J. (1994). *Medicine, rationality, and experience: An anthropological perspective*. Cambridge: Cambridge University Press.
- Good, B. J. (1997). Studying Mental Illness in Context: Local, Global, or Universal? *Ethos*, 25(2), 230–248.
- Good, B. J. (2010). Medical anthropology and the problem of belief . In B. J. Good., M. M. Fischer., S. S. Willen, & M. J. Good, *A reader in medical anthropology: Theoretical trajectories, emergent realities* (pp. 64–76). West Sussex: Wiley-Blackwell .
- Gould, N. (2010). *Mental health social work in context*.. London: Routledge.
- Gray, S. J. (2000). A memory of loss: ecological politics, local history, and the evolution of the Karimojong violence. *Human Organization*, 59(4), 401–418.
- Gray, S. J. (2010). ‘Someone dies in your lap’: Structural, ecological and political effects on child and maternal healthcare decisions, Moroto district, Uganda, 2004. *Nomadic Peoples*, 14(2), 44–71.
- Gray, S. J., Akol, A. A., & Sundal, M. (2007). Social and demographic effects of the crisis in Karamoja: a preliminary report. *The Uganda Journal*, 5, 15–26.
- Green, D. (2008). *From poverty to power: how active citizens and effective states can change the world*. Oxford: Oxfam International.
- Green, J., & Thorogood, N. (2004). *Qualitative methods for health research*. London: Sage Publications.
- Gureje, O., Simon, G. E., Ustun, T. B., & Goldberg, D. P. (1997). Somatization in cross-cultural perspective: A World Health Organization study in primary care. *American Journal of Psychiatry*, 154(7), 989–995.
- Gureje, O., & Stein, D. J. (2014). Disorders, diagnosis, and classification. In D. Bhugra & K. Bhui (Eds.), *Textbook of Cultural Psychiatry*, (pp. 27–40). Cambridge: Cambridge University Press.
- Hammen, C., & Compas, B. E. (1994). Unmasking unmasked depression in children and adolescents: the problem of comorbidity. *Clinical Psychology Review*, 14(6), 585–603.
- Hannerz, U. (2012). Being There. . . and There . . . and There! Reflections on multi-site ethnography. In C.G. Robben & J. A. Sluka (Eds.), *Ethnographic fieldwork: An anthropological reader* (pp. 399–408). (2nd ed.). West Sussex: Wiley & Sons Inc.
- Hammond-Tooke, W. D. (1989). *Rituals and medicines: Indigenous healing in South Africa*. Johannesburg: AD. Donker (PTY) LTD.

- Hardman, C. (2001). Can there be an anthropology of children? *Childhood*, 8(4), 501–517.
- Hardon, A., Broonmongkon, P., Streefland, P., Tan, M. L., Hongvinatana, T., Van der Geest, S., . . . Varkevisser, C. (2001). *Manual for applied health research. Anthropology of health and healthcare*. Amsterdam: Het Spinhuis.
- Hare-Mustin, R. T., & Marecek, J. (1997). Abnormal and clinical psychology: The politics of madness. In D. Fox, & I. Prilleltensky, *Critical psychology: An Introduction* (pp. 104–120). London: SAGE Publications.
- Harrowing, J. N., Mill, J., Spiers, J., Kulig, J., & Kipp, W. (2010). Critical ethnography, Cultural safety, and international nursing research. *International Journal of Qualitative Methods*, 9(3), 240–251.
- Haslam, N. (2005). Dimensions of folk psychiatry. *Review of General Psychology*, 9(1), 35–47.
- Hatfield, R., & Davis, J. (2006). *Global review of the economies of pastoralism. Prepared for the World Initiative for Sustainable Pastoralism*. Nairobi: International Union for the Conservation of Nature (IUCN).
- Helman, C. G. (1994). *Culture, health and illness* (3rd ed.). Oxford: Butterworth-Heinemann.
- Helman, C. G. (2007). Anthropology and its contributions. In K. Bhui, & D. Bhugra, *Culture and mental health: A comprehensive textbook* (pp. 11–15). Oxford: Oxford University Press.
- Henning, E., Van Rensburg, W., & Smit, B. (2009). *Finding your way in qualitative research*. Pretoria: Van Schaik Publishers.
- Hergenhahn, B. R. (2009). *An introduction to the history of psychology* (6th ed.). Belmont: Wadsworth Cengage Learning.
- Herrman, H., & Swartz, L. (2007). Promotion of mental health in poorly resourced countries. *Lancet*, 1195–1197. doi:10.1016/S0140-6736(07)61244-6
- Hornor, G. (2004). Sexual behaviour in children: Normal or not? *Journal of Pediatric Healthcare*, 18(2), 57–64.
- Horton, R. (2007). Launching the new movement for mental health. *Lancet*, 1241–1252. doi:10.1016/S0140-6736(07)61242-2-4
- Hoven, C. W., Doan, T., Musa, G. J., Jaliashvili, T., Duarte, C. S., Ovuga, E., . . . Force, W. A. (2008). Worldwide child and adolescent mental health begins with awareness: A preliminary assessment in nine countries. *International Review of Psychiatry*, 20(3), 261–270.

- Human Rights Watch (HRW). (2007). *“Get the gun!” Human rights violations by Uganda’s national army in law enforcement operation in Karamoja region* (Vol. 19). New York: Human Rights Watch.
- Human Rights Watch (HRW). (2014). *“How Can We Survive Here?” The Impact of Mining on Human Rights in Karamoja, Uganda*. New York: Human Rights Watch.
- Igreja, V., Dias-Lambranca, B., & Richters, A. (2008). Gamba spirits, gender relations, and healing in post-civil war Gorongosa, Mozambique. *Journal of the Royal Anthropological Institute (N.S.)*, 14, 353–371.
- Igreja, V., Kleijn, W., & Richters, A. (2006). When the war was over, little changed: Women’s posttraumatic suffering after the war in Mozambique. *The Journal of Nervous and Mental Disease*, 194(7), 502–509. doi: 10.1097/01.nmd.0000228505.36302.a3
- Ikwuka, U., Galbraith, N., & Nyatanga, L. (2013). Causal attribution of mental illness in south-eastern Nigeria. *International Journal of Social Psychiatry [serial online]*, 274–279. doi:10.1177/0020764013485331.
- Jabs, L. (2007). Where two elephants meet, the grass suffers: a case study of intractable conflict in Karamoja, Uganda. *American Behavioral Scientist*, 50(11), 1498–1519.
- Jacob, K. S. (2017). Mental health services in low-income and middle-income countries. *Lancet*, 4: 128. dx.doi.org/10.1016/ S2215-0366(16)30423-0.
- Jacob, S. K., Mirsa, I. S., Garrido-Cumbrera, M., Seedat, S., Mari, J. J., Screenivas, V., & Saxena, S. (2007). Mental health systems in countries: where are we now? *Lancet*, 370, 1061–1077.
- Jacob, K. S., & Patel, V. (2014). Classification of mental disorders: a global mental health perspective. *Lancet*, 383: 1433–35.
- Jacoby, A., Wang, W., Dang Vu, T., Snape, D., Aydemir, N., Parr, J., . . . Baker, G. (2008). Meanings of epilepsy in its sociocultural context and implications for stigma: findings from ethnographic studies in local communities in China and Vietnam. *Epilepsy Behaviour*, 12, 286–297.
- Jenkins, J. (1996). Culture, emotion, and psychiatric disorders. In C. F. Sargent & T. Johnson (Eds), *Medical anthropology: Contemporary theory and method* (pp. 71–87). Westpot: Praeger Publishers.

- Jenkins, J. H. (2018). Anthropology and psychiatry: A contemporary convergence for global mental health. In D. Bhugra & K. Bhui (Eds.), *Textbook of cultural psychiatry* (pp. 18–34). Cambridge: Cambridge University Press.
- Jilek-Aall, L., Jilek, M., Kaaya, J., Mkombachepa, L., & Hillary, K. (1997). Psychosocial study of epilepsy in Africa. *Social Science & Medicine*, 45, 783–795.
- Jones, L. J. (1994). *The social context of health and health work*. London: MacMillan Press Ltd.
- Jones, L., Asare, B. J., El Masri, M., Mohanraj, A., Sherief, H., & van Ommeren, M. (2009). Severe mental disorders in complex emergencies. *Lancet*, 374, 654–661.
- Jordans, M. J. D., & Tol, W. A. (2013). Mental health in humanitarian settings: shifting focus to care systems. *Int Health*, 5: 9–10. doi:10.1093/inthealth/ih005.
- Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., & Pollitt, P. (1997). “Mental health literacy”: a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *Medical Journal of Australia*, 166: 182-186. doi.org/10.5694/j.1326-5377.1997.tb140071.x
- Kaabong District Local Government. (2010). *Three year rolling plan, 2010/2011–2012/2013*. Kaabong: KDLG.
- Kaaya, S. F., Mbwambo, J. K., Smith Fawzi, M. C., Van Den Borne, H., Schaalma, H., & Leshabari, M. T. (2010). Understanding women's experiences of distress during pregnancy in Dar es Salaam, Tanzania. *Tanzania Journal of Health Research*, 12(1), 36–46.
- Karasz, A. (2005). Cultural differences in conceptual models of depression. *Social Science & Medicine*, 60, 1625–1635.
- Karban, K. (2011). *Social work and mental health*. Polity Press: Cambridge.
- Keikelame, M. J., & Swartz, L. (2013). A lay carer's story about epilepsy in an urban South African context: They call it an illness of falling or an illness of fitting because a person shakes and eventually falls. *Epilepsy & Behavior*, 28, 512–518. doi:10.1016/j.yebeh.2013.05.025
- Kerr, C., Nixon, A., & Angalakuditi, M. (2011). The impact of epilepsy on children and adult patients' lives: Development of a conceptual model from qualitative literature. *Seizure*, 20, 764–774.
- Kessler, R. C., Alonso, J., Chatterji, S., & He, Y. (2014). The epidemiology and impact of mental disorders. In V. Patel., H. Minas., A. Cohen, & M. J. Prince (Eds.), *Global*

- mental health: Principles and practice* (pp. 82–101). Oxford: Oxford University Press.
- Kieling, C., Graeff-Martins, A. S., Hamoda, H., & Rodhe, L. A. (2014). Child and adolescent mental health. In V. Patel, H. Minas, A. Cohen, & M. J. Prince (Eds.), *Global mental health: Principles and practice* (pp. 335–353). Oxford: Oxford University Press.
- Kielmann, K., Cataldo, F., & Seeley, J. (2011). *Introduction to qualitative research methodology*. London: Department for International Development (DFID).
- Kigozi, F., Ssebunnya, J., Kizza, D., Cooper, S., & Ndyabangi, S. (2010). An overview of Uganda's mental healthcare system: results from an assessment using the World Health Organization's Assessment Instrument for Mental Health Systems (WHO-AIMS). *International Journal of Mental Health Systems*, 4(1).
- Kilbourne, A. M., Beck, K., Spaeth-Rublee, B., Ramanuj, P., O'Brien, R. W., Tomoyasu, N., & Pincus, H. A. (2018). Measuring and improving the quality of mental health care: a global perspective. *World Psychiatry*, 17:30–38.
- Kinyanda, E., Nakiboneka, V., Ojambo, O. R., Were-Oguttu, J., Gayflor, V., Liebling-Kalifani, H., & Diawara-Howard, L. (2010). Prevalence and correlates of psychological distress as seen in post-conflict Liberia. *African Journal of Traumatic Stress*, 1(2), 96–102.
- Kirk, S. (2007). Methodological and ethical issues in conducting qualitative research with children and young people: a literature review. *International Journal of Nursing Studies*, 44, 1250–1260.
- Kirmayer, L. J., & Gomez-Carrillo, A. (2018). Cultural clinical psychology and psychiatry. In: Maercker, A., Heim, E. & Kirmayer, L. J. (Eds.) *Cultural Clinical Psychology and PTSD* (pp. 3-21). Boston: Hogrefe
- Kirmayer, L. J. (1984). Overview: Culture, affect and somatization. *Transcultural Psychiatric Research Review*, 21.
- Kirmayer, L. J. (2006). Beyond the 'New cross-cultural psychiatry': Cultural biology, discursive psychology and the ironies of globalization. *Transcultural Psychiatry*, 43(1), 126–144.
- Kirmayer, L. J. (2007). Cultural psychiatry in historical perspective. In D. Bhugra, & K. Bhui (Eds.), *Textbook of cultural psychiatry* (pp. 1–19). Cambridge: Cambridge University Press.

- Kirmayer, L. J. (2012). Culture and context in human rights. In M. Dudley, D. Silove, & F. Gale (Eds.), *Mental health and human rights: vision, praxis and courage* (pp. 95–112). Oxford: Oxford University Press.
- Kirmayer, L. J. (2018). Cultural psychiatry in historical perspective. In D. Bhugra & K. Bhui (Eds.), *Textbook of cultural psychiatry* (pp. 1–17). Cambridge: Cambridge University Press.
- Kirmayer, L. J., & Bhugra, D. (2009). Culture and mental illness: Social context and explanatory models. In I. M. Salloum & J. E. Mezzich (Eds.), *Psychiatric diagnosis: Patterns and prospects* (pp. 29–37). New York: John Wiley & Sons.
- Kirmayer, L. J., & Pedersen, D. (2014). Towards a new architecture for global mental health. *Transcultural Psychiatry*, 51(6): 759–776. DOI: 10.1177/1363461514557202.
- Kirmayer, L. J., & Sartorius, N. (2007). Cultural models and somatic syndromes. *Psychosomatic Medicine*, 69, 832–840.
- Kirmayer, L. J., & Swartz, L. (2014). Culture and global mental health. In V. Patel, H. Minas, A. Cohen, & M. J. Prince (Eds.), *Global mental health: Principles and practice* (pp. 41–62). Oxford: Oxford University Press.
- Kisanji, D. (1995). Attitudes and beliefs about disability in Tanzania. In R. McConkey & B. O’Toole (Eds.), *Towards the new millennium: innovations in developing countries for people with disabilities* (pp. 1–18). Lancashire: Chorley.
- Kleinman, A. (1977). Depression, somatization and the new cross-cultural psychiatry. *Social Science and Medicine*, 11, 3–10.
- Kleinman, A. (1980). *Patients and healers in the context of culture. An exploration of the borderland between anthropology, medicine and psychiatry*. Berkeley: University of California Press.
- Kleinman, A. (1982). Neurasthenia and depression: a study of somatisation and culture in China. *Cultural Medical Psychiatry*, 6, 117–120.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books, Inc.
- Kleinman, A. (1999). Moral experience and ethical reflection: Can ethnography reconcile them? A quandary for “The new bioethics”. *Daedalus*, 128, 69–99.
- Kleinman, A. (2000). The violences of everyday life: The multiple forms and dynamics of social violence. In V. Das, A. Kleinman, R. Mamphela, & R. Pamela (Eds.), *Violence and subjectivity* (pp. 226–241). Berkeley: University of California Press.

- Kleinman, A. (2009). Global mental health: a failure of humanity. *Lancet*, 374, 603–604.
- Kleinman, A. (2010). The art of medicine: Four social theories of global health. *Lancet*, 375, 1518–1519.
- Kleinman, A., & Becker, A. E. (2000). Anthropology and psychiatry. In B. Sadock, & V. Sadock (Eds.), *Comprehensive textbook of psychiatry* (7th ed., Vol. 1, pp. 470–475). New York: Lippincott Williams & Wilkins.
- Kleinman, A., & Good, B. J. (2010). Introduction to culture and depression. In R. LeVine (Ed.), *Psychological anthropology: A reader on self in culture* (pp. 112–116). West Sussex: Wiley-Blackwell.
- Kleintjes, S., Lund, C., & Flisher, A. J. & MHaPP Research Programme Consortium. (2010). A situational analysis of child and adolescent mental health services in Ghana, Uganda, South Africa and Zambia. *African Journal of Psychiatry*, 13, 132–139.
- Knighton, B. (2003). The state as raider among the Karimojong: ‘Where there are no guns, they use the threat of guns’. *Africa*, 73(3), 427–455.
- Knighton, B. (2005). *The vitality of the Karamojong religion: Dying tradition or living faith?* Hants: Ashgate Publishing Ltd.
- Knighton, B. (2010). ‘Disarmament’: The end or fulfilment of cattle raiding? *Nomadic Peoples*, 14(2), 123–146.
- Kohrt, B. A., Asher, L., Bhardwaj, A., Fazel, M., Jordans, M, J, D., Mutamba, B. B., . . . Patel, V. (2018). The Role of Communities in Mental Health Care in Low- and Middle-Income Countries: A Meta-Review of Components and Competencies. *Int. J. Environ. Res. Public Health*, 15: 1279. doi:10.3390/ijerph15061279.
- Kohrt, B. A., & Hruschka, D. J. (2010). Nepali concepts of psychological trauma: The role of idioms of distress, ethnopsychology, and ethnophysiology in alleviating suffering and preventing stigma. *Culture, Medicine and Psychiatry*, 34(2), 322–352. doi:10.1007/s11013-010-9170-2.
- Kpobi, L., & Swartz, L. (2019). Indigenous and faith healing in Ghana: A brief examination of the formalising process and collaborative efforts with the bio-medical health system. *Afr J Prm Health Care Fam Med*, 11(1). doi.org/10.4102/phcfm. v11i1.2035.
- Kpobi, L., & Swartz, L. (2018). Explanatory models of mental disorders among traditional and faith healers in Ghana. *International Journal of Culture and Mental Health*. doi:10.1080/17542863.2018.1468473

- Krätli, S. (2010). Karamoja with the rest of ‘the rest of Uganda.’ Preface. *Nomadic Peoples*, 14(2), 3–23.
- Krippendorff, K. (2004). *Content analysis: Introduction to its methodology*. London: SAGE Publications.
- Lavenda, R. H., & Schultz, E. (2008). *Anthropology: What does it mean to be human?* Oxford: Oxford University Press.
- Lee, D. T., Kleinman, J., & Kleinman, A. (2007). Rethinking depression: An ethnographic study of the experiences of depression among Chinese. *Harvard Review Psychiatry*, 15, 1–8.
- Lefley, H. (2010). Mental health systems in a cross-cultural context. In T. L. Scheid & T. N. Brown (Eds.), *A handbook for the study of mental health: Social contexts, theories, and systems* (pp. 135–161). Cambridge: Cambridge University Press.
- LeVine, R. A. (2010). Human variations: A population perspective on psychological processes. In R. A. LeVine (Ed.), *Psychological anthropology: A reader on self in culture* (pp. 53–59). West Sussex: Wiley-Blackwell.
- Li, S., Wu, J., Wang, W., Jacoby, A., de Boer, H., & Sander, J. W. (2010). Stigma and epilepsy: The Chinese perspective. *Epilepsy & Behavior*, 17, 242–245.
- Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *Lancet*, 367, 528–529.
- Little, D. P., McPeak, J., & Barret, C. B. (2008). *Challenging orthodoxies: understanding poverty in pastoral areas of East Africa*. Washington: USAID/World Bank.
- Liu, N. H., Daumit, G. L., Dua, T., Aquila, R., Charlson, F., Cuijpers, P., Druss, B., . . . Saxena, S. (2017). Excess mortality in persons with severe mental disorders: a multilevel intervention framework and priorities for clinical practice, policy and research agendas. *World Psychiatry*, 16:30–40.
- Lock, M. (1993). Cultivating the body: anthropology and Epistemologies of bodily practice and knowledge. *Annual Review of Anthropology*, 22, 133–155.
- Lock, M., & Scheper-Hughes, N. (1996). A critical-interpretive approach in medical anthropology: Rituals and routines of discipline and dissent. In C. F. Sargent & T. M. Johnson (Eds.), *Medical anthropology: Contemporary theory and method* (pp. 41–70). Westpot: Praeger Publishers.

- Lund, C., Brooke-Sumner, C., Baingana, F., Baron, E. C., Breuer, E., Chandra, P., . . . Saxena, S. (2018). Social determinants of mental disorders and the Sustainable Development Goals: a systematic review of reviews. *Lancet Psychiatry*, 5, 357–69.
- Lund, C., Stansfeld, S., & De Silva, M. (2014). Social determinants of mental health. In V. Patel, H. Minas, A. Cohen, & M. J. Prince (Eds.), *Global mental health: Principles and practice* (pp. 116–136). Oxford: Oxford University Press.
- Lund, C., & Swartz, L. (1998). Xhosa-speaking schizophrenic patients' experience of their condition: psychosis and *amafufunyana*. *S.Afr. J. Psychol*, 28(2).
- Madison, D. S. (2012). *Critical ethnography: Method, ethics, and performance* (2nd ed.). Los Angeles: SAGE Publications Ltd.
- Mamdani, M. (1982). Karamoja: Colonial roots of famine in North-East Uganda. *Review of African Political Economy*, 25, 66–73.
- Marchi, P. (2010). The right to health of nomadic groups. *Nomadic Peoples*, 14(1), 31–50. doi:10.3167/np.2010.140103.
- Mathews, M. (2011). Assessment and comparison of culturally based explanations of mental disorder among Singaporean Chinese youth. *International Journal of Social Psychiatry*, 57(1), 3–17.
- Maxwell, J. A. (2012). The importance of qualitative research for causal explanation in education. *Qualitative Inquiry*, 18(18), 655–661.
- Mbithi, J. S. (1975). *Introduction to African religion*. London: Heinemann.
- McCarthy, J. (2005). Teenagers with severe learning difficulties and behavioural problems: what to do. *Current Paediatrics*, 15, 127–132. doi:10. 1016/j.cupe.2004.12.010
- Mckenzie, J. A., McConkey, R., & Adnams, C. (2013). Intellectual disability in Africa: implications for research and service development. *Disability and Rehabilitation. An International, Multidisciplinary Journal*, 35(20), 1750–1755.
- Mehta, N., & Thornicroft, G. (2014). Stigma, discrimination, and promoting human rights. In V. Patel, H. Minas, A. Cohen, & M. J. Prince (Eds.), *Global mental health: Principles and practice* (pp. 401–424). Oxford: Oxford University Press.
- Ministry of Health (MoH). (1999). *National Health Policy*. Entebbe: Ministry of Health.
- Ministry of Health. (2000). *Health Sector Strategic Plan (HSSP) 2000/01– 2004/5*. (Vol. 1). Kampala: Ministry of Health.
- Ministry of Health. (2005). *Health Sector Strategic Plan (HSSP) 2005/06–2009/10* (Vol. 2). Kampala: Ministry of Health.

- Mirzeler, M., & Young, C. (2000). Pastoral Politics in the Northeast Periphery in Uganda: AK-47 as Change Agent. *The Journal of Modern African Studies*, 38(3), 407–429.
- Mkutu, K. A. (2007). Impact of small arms insecurity on the public health of pastoralists in the Kenya-Uganda border regions. *Crime, Law and Social Change*, 47, 33–56.
- Mkutu, K. A. (2008). Disarmament in Karamoja, Northern Uganda: Is this a solution for localised violent inter and intra-communal conflict? *The Round Table*, 97(394), 99–120.
- Mkutu, K. A. (2010). Complexities of livestock raiding in Karamoja. *Nomadic Peoples*, 14(2), 87–105.
- Molodynski, A., Cusack, C. & Nixon, J. (2017). Mental healthcare in Uganda: desperate challenges but real opportunities. *BJPSYCH INTERNATIONAL*, 14: 4.
- Moroto District Local Government. (2010). *Three-Year Rolling District Integrated Development Plan (DDP), 2010/2011–2012/2013*. Moroto: MDLG.
- Moroto District Local Government. (2018). *District Family Planning Costed Implementation Plan, 2018/19-2022/23*. Moroto: MDLG.
- Mugisha, J., Hanlon, C., Knizek, B.L., Ssebunnya, J., Vancampfort, D., Kinyanda, E. & Kigozi, F. (2019). The experience of mental health service users in health system strengthening: lessons from Uganda. *Int J Ment Health Syst*, 13:60
<https://doi.org/10.1186/s13033-019-0316-5>.
- Muhwezi, W. W., Okello, E. S., Neema, S., & Musisi, S. (2008). Caregivers' experiences with major depression concealed by physical illness in patients recruited from central Ugandan primary healthcare centres. *Qualitative Research*, 18(8), 1094–1114.
- Murchison, J. M. (2010). *Ethnographic essentials: Designing, conducting and presenting your research*. San Francisco: Jossey-Bass.
- Murray, L. K., Dorsey, S., Haroz, E., Lee, C., Alsiahy, M. M., Haydary, A., . . . Bolton, P. (2013). A common elements treatment approach for adult mental health problems in low- and middle-income countries. *Cognitive and Behavioural Practice*, 21, 111–123.
- Musisi, S., Okello, E. S., & Abbo, C. (2010). Culture and traditional healing in conflict/post-conflict societies. *African Journal of Traumatic Stress*, 1(2), 80–85.
- Närman, A. (2003). Karamoja: Is peace possible? *Review of African Political Economy*, 30(95), 129–133.
- Ndeti, D. M., & Mburu, J. (2006). History of Psychiatry. In D. M. Ndeti, C. J. Othieno, G. Kilonzo, J. Mburu, & O. Tarek (Eds.), *The African textbook of clinical psychiatry and*

- mental health* (pp. 6–10). Nairobi: The African Medical Research Foundation (AMREF).
- Ndyanabangi, S., Basangwa, D., Lutakome, J., & Mubiru, C. (2004). Uganda mental health country profile. *International Review of Psychiatry*, 16(1–2), 54–62.
- Newton, C. R., & Garcia, H. H. (2012). Epilepsy in poor regions of the world. *Lancet*, 380, 1193–1201.
- Nichter, M. (2010). Idioms of distress revisited. Commentary. *Culture, Medicine and Psychiatry*, 34, 401–416.
- Nightingale, D., & Neilands, T. (1997). Understanding and practicing critical psychology. In D. Fox & I. Prilleltensky (Eds.), *Critical psychology: An introduction* (pp. 68–84). London: Sage Publications.
- Njenga, F. (2009). Perspectives of intellectual disability in Africa: epidemiology and policy services for children and adults. *Current Opinion in Psychiatry*, 22, 457–461.
- Nori, M., Taylor, M., & Sensi, A. (2008). *Pastoral land rights, livelihoods and adaptation to climate change*. WISP. Nottingham: Russell Press.
- Novelli, B. (1988). *Aspects of Karimojong ethnosociology*. Museum Combonianum no.44. Kampala: Comboni Missionaries.
- Nuri, N.N., Sarker, M., Ahmed, H. U., Hossain, M, D., Beiersmann, C., & Jahn, A. (2018). Pathways to care of patients with mental health problems in Bangladesh. *International Journal of Mental Health Systems*, 12:39. doi.org/10.1186/s13033-018-0218-y.
- O’Keefe, M. (2010). Chronic crises in the arc of insecurity: a case study of Karamoja. *Third World Quarterly*, 31(8), 1271–1295.
- Office for the Coordination of Humanitarian Affairs . (2008). *Focus on Karamoja. Special Report No. 2. Urgent humanitarian needs from August to October 2008*. New York: United Nations.
- Office for the Coordination of Humanitarian Affairs. (2009). *Focus on Karamoja. Special Report No. 4 – January to June 2009*. New York: United Nations.
- Office for the Coordination of Humanitarian Affairs. (2011). *Uganda humanitarian profile*. New York: United Nations.
- Okello, E. S., & Ekblad, S. (2006). Lay concepts of depression among the Baganda of Uganda: A pilot study. *Transcultural Psychiatry*, 43(2), 287–313.

- Okello, E. S., & Musisi, S. (2006). Depression as a clan illness (eByekika): an indigenous model of psychotic depression among the Baganda of Uganda. *World Cultural Psychiatry Research Review*, 1, 60–73.
- Okello, E. S., & Neema, S. (2007). Explanatory models and help-seeking behaviour: Pathways to psychiatric care among patients admitted for depression in Mulago Hospital, Kampala, Uganda. *Qualitative Health Research*, 17(1), 14–25.
- Orley, J. H. (1970). *Culture and mental illness: A study from Uganda*. Nairobi: East African Publishing House.
- Ovuga, E. (Ed.). (2006). *Psychiatry for primary healthcare in Uganda*. Kampala: Fountain Publishers.
- Oyebode, F. (2006). History of psychiatry in West Africa. *International Review of Psychiatry*, 18(4), 319–325.
- Patel, V. (1995). Explanatory models of mental illness in Sub-Saharan Africa. *Social Science & Medicine*, 40(9), 1291–1298.
- Patel, V. (1998). *Culture and common mental disorders in Sub Saharan Africa*. East Sussex: Psychology Press on behalf of Maudsley.
- Patel, V. (2005). Social origins, biological treatments: The public health implications of common mental disorders in India. *Indian Journal of Psychiatry*, 47, 15–20.
- Patel, V. (2009). The future of psychiatry in low- and middle-income countries. *Psychological Medicine*, 39, 1759–1762.
- Patel, V. (2014a). Why mental health matters to global health. *Transcultural Psychiatry*, 51(6), 777–789. doi:10.1177/1363461514524473.
- Patel, V. (2014b). Rethinking mental health care: bridging the credibility gap. *Intervention*, 12(1): 15-20.
- Patel, V., Boyce, N., Collins, P.Y., Saxena, S., & Horton, R. (2011). *Lancet*, 378. A renewed agenda for global mental health. DOI:10.1016/S01406736(11)61385-8.
- Patel, V., Flisher, A. J., Nikapota, A., & Malhotra, S. (2008). Promoting child and adolescent mental health in low and middle income countries. *Journal of Child Psychology and Psychiatry*, 49(3), 313–334.
- Patel, V., & Kleinman, A. (2003). Poverty and common mental disorders in developing countries. *Bulletin of the World Health Organization*, 81(8), 609–615.
- Patel, V., Kleinman, A., & Saraceno, B. (2012). Protecting the human rights of people with mental illnesses: A call for action for global mental health. In M. Dudley, D. Silove,

- & F. Gale (Eds), *Mental Health and Human Rights: vision, praxis and courage* (pp. 362–375). Oxford: Oxford University Press.
- Patel, V., Saxena, S., Lund, C., Thornicroft, G., Baingana, F., Bolton, P., . . . Unutzer, J. (2018). The Lancet Commission on global mental health and sustainable development. *Lancet*, published online Oct 9. doi.org/10.1016/S0140-6736(18)31612-X.
- Patel, V., Simbine, A. P., Soares, I. C., Weiss, H. A., & Wheeler, E. (2007). Prevalence of severe mental and neurological disorders in Mozambique: a population-based survey. *Lancet*, 370, 1055–1060.
- Pattanayak, R. D., & Mehta, M. (2012). Childhood and adolescent depression. In U. Nayar (Ed.), *Child and adolescent mental health* (pp. 21–38). New Delhi: SAGE Publication Inc.
- Peoples, J., & Bailey, G. (2009). *Humanity: An introduction to cultural anthropology*. Belmont: Wadsworth Cengage Learning.
- Pereira, B., Andrew, G., Pednekar, S., Pai, R., Pelto, P., & Patel, V. (2007). The explanatory models of depression in low income countries: Listening to women in India. *Journal of Affective Disorders*, 102, 209–218.
- Perry, M. J. (1996). The relationship between social class and mental disorder. *The Journal of Primary Prevention*, 17(1), 17-30.
- Peterson, I., Bhana, A., Flisher, A. J., Swartz, L., & Richer, L. (Eds.). (2010). *Promoting mental health in scarce-resource contexts: Emerging evidence and practice*. Cape Town: HSRC Press.
- Pierre, J. (2003). The illness experience: state of knowledge and perspectives for research. *Sociology of Health & Illness*, 25, 4–22.
- Pike, I. L., Straight, B., Oesterle, M., Hilton, C., & Lanyasunya, A. (2010). Documenting the health consequences of endemic warfare in three pastoralist communities of northern Kenya: a conceptual framework. *Social Science & Medicine*, 70, 45–52.
- Pilgrim, D. (2009). *Key concepts in mental health*. (2nd ed.). Los Angeles: SAGE Publications Ltd.
- Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: Analysing qualitative data. *BMJ*, 320, 114-116.
- Prilleltensky, I. (1999). Critical psychology foundations for the promotion of mental health. *Annual Review of Critical Psychology*, 1, 100–118.

- Prince, M. J., Rahman, A., Mayston, R., & Weobong, B. (2014). In V. Patel, H. Minas, A. Cohen, & M. Prince (Eds.), *Global mental health: Principles and practice* (pp. 102–115). Oxford: Oxford University Press.
- Pringle, Y. (2019). *Psychiatry and Decolonisation in Uganda*. London: Palgrave Macmillan.
- Quam, M. D. (1996). Creating peace in an armed society: Karamoja, Uganda. *African Studies Quarterly*, 1(1), 33–46.
- Quinn, N. (2007). Beliefs and community responses to mental illness in Ghana: the experiences of family carers. *International Journal of Social Psychiatry*, 53(2), 175–188.
- Randal, J., Thornicroft, G., Brohan, E., Kassam., A., Lewis-Holmes, E., & Mehta, N. (2012). Stigma and discrimination. Critical human rights issues for mental health. In M. Dudley, D. Silove, & F. Gale (Eds.), *Mental health and human Rights: Vision, praxis, and courage* (pp. 113–235). Oxford: Oxford University Press.
- Rasmussen, S. (2008). Introduction – Health knowledge and belief systems in Africa. In T. Falola, & M. M. Heaton (Eds.), *Health knowledge and belief systems in Africa* (pp. 3–29). Durham: Carolina Academic Press.
- Rathod, S., Pinninti, N., Irfan, M., Gorczynski, P., Rathod, P., Gega, L., & Naeem, F. (2017). Mental health service provision in low-and middle-income counties. *Health Services Insight*, 10: 1-7. doi.org/10.1177/1178632917694350.
- Raviola, G., Becker, A, N., & Farmer, P. (2011). A global scope for global health—including mental health. *Lancet*, 378. DOI:10.1016/S01406736(11)60941-0.
- Rylko-Bauer, B., & Farmer, P. (2016). Structural violence, poverty, and social suffering. In D. Brady & L. M. Burton (Eds.), *The Oxford Handbook of the social science of poverty* (pp. 47-74). Oxford: Oxford University Press.
- Razzouk, D., Sharan, P., Gallo, C., Gureje, O., Lamberte, E. E., de Jesus Mari, J., . . . Saxena, S. (2010). Scarcity and inequity of mental health research resources in low- and-middle income countries: A global survey. *Health Policy*, 94, 211–220.
- Read, U. M., Adiibokah, E., & Nyame, S. (2009). Local suffering and the global discourse of human rights: An ethnographic study of responses to mental illness in rural Ghana. *Globalization and Health*, 5(13). doi 10.1186/1744-8603-5-13
- Reavley, N. J., & Jorm, A. F. (2011). Stigmatising attitudes towards People with mental disorders: Findings from an Australian national survey of mental health literacy and

- stigma. *Australian and New Zealand Journal of Psychiatry*, 45, 1086–1093.
doi:10.3109/00048674.621061
- Reis, R. (2013). Children enacting idioms of witchcraft and spirit possession as a response to trauma: Therapeutically beneficial, and for whom? *Transcultural Psychiatry*, 50(5), 622–643.
- Republic of Uganda. (2000). *Draft Mental Health Policy (MHP)*. Kampala: Ministry of Health, Uganda.
- Republic of Uganda. (2007). *Karamoja Integrated Disarmament and Development Programme: creating conditions for promoting human security and recovery in Karamoja, 2007/2008–2009/2010*. Kampala: Office of the Prime Minister.
- Republic of Uganda. (2009). *Karamoja action plan for food security (2009–2014) in Karamoja agricultural and production zones (Karamoja Region). Programme document*. Kampala: Republic of Uganda.
- Republic of Uganda. (2010). *The second national health policy: Promoting people's health for socio-economic development*. Kampala: Ministry of Health.
- Republic of Uganda. (2015). Office of the Prime Minister, Ministry for Karamoja Affairs, *Karamoja Integrated Development Plan 2 (KIDP 2) 2015-2020*. Kampala: RoU.
- Robben, C. G., & Sluka, J. A. (2012). *Ethnographic fieldwork: An anthropological reader*. (2nd ed.). West Sussex: Wiley & Sons Inc.
- Roberts, B., Odong, V. N., Browne, J., Ocaka, K. F., Geissler, W., & Sondorp, E. (2009). An exploration of social determinants of health amongst internally displaced persons in northern Uganda. *Conflict and Health* 2009, 3(10). doi:1186/1752-1505-3-10
- Rose, N. (2007). Beyond medicalisation. *Lancet*, 369, 700–701.
- Rosen, T., & McGorry, P. (2012). The Human Rights of People with Severe and Persistent mental illness. In M. Dudley, D. Silove, & F. Gale (Eds.), *Mental health and human rights: Vision, praxis, and courage* (pp. 297–320). Oxford: Oxford University Press.
- Rubel, A., & Hass, M. R. (1996). Ethnomedicine. In C. F. Sargent & T. M. Johnson (Eds.), *Medical anthropology: Contemporary theory and method* (pp. 113–130). Westport: Praeger Publishers.
- Rugadya, M. A., & Kamusiime, H. (2013). Tenure in mystery: the status of land under wildlife, forestry and mining concessions in Karamoja region, Uganda. *Nomadic Peoples*, 17(1), 33–65. doi:10.3167/np.2013.170103

- Rüsch, N., & Corrigan, P. W. (2013). Stigma, discrimination and mental health. In L. Knifton, & N. Quinn (Eds.), *Public mental health: Global perspectives* (pp. 95–100). Berkshire: Open University Press.
- Said, E. W. (1978). *Orientalism: Western representations of the orient*. New York: Pantheon Books.
- Saint, M., & White, E. (2010). Ontological assumptions of the medical model of psychiatry. *FALSAFEH/Philosophy, Ethics, and Humanities in Medicine*, 38(1), 111–126.
- Saraceno, B., Ommeren, M., Batniji, R., Cohen, A., Gureje, O., Mahoney, J., . . . Underhill, C. (2007). Barriers to improvement of mental health services in low-income and middle-income countries. *Lancet* [serial online], 1164–1174. doi:10.1016/S0140-6736(07)61263-x.
- Sartorius, N. (2007). Stigma and mental health. *Lancet* [serial online], 810–811. doi:10.1016/S0140-6736(07)61245-8.
- Saxena, S., Thornicroft, G., Knapp, M., & Whiteford, H. (2007). Resources for mental health: scarcity, inequity, and inefficiency. *Lancet*, 370, 878–889.
- Scheper-Hughes, N. (1992). *Death without weeping: the violence of everyday life in Brazil*. Berkeley: University of California Press.
- Scheper-Hughes, N., & Lock, M. M. (1987). The mindful body: A prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly*, 1(1), 6–41.
- Schlee, G. (2013). Why states still destroy pastoralism and how they can learn that in their own interest they should not. *Nomadic Peoples*, 17(2), 6–19. doi:10.3167/np.213.170203.
- Schnyder, N., Panczak, R., Groth, N., & Schultze-Lutter, F. (2017). Association between mental health-related stigma and active help-seeking: systematic review and meta-analysis. *The British Journal of Psychiatry*, 210: 261–268. doi: 10.1192/bjp.bp.116.189464.
- Selim, N., & Satalkar, P. (2008). Perceptions of mental illness in a Bangladeshi village. *BRAC University Journal*, 1, 47–57.
- Sen, A. (1999). *Development as freedom*. Oxford: Oxford University Press.
- Shatkin, J. P., & Belfer, M. L. (2004). The global absence of child and adolescent mental health policy. *Child and Adolescent Mental Health*, 9(3), 104–108.

- Shibre, T., Teferra, S., Morgan, C., & Alem, A. (2010). Exploring the apparent absence of psychosis amongst the Borana pastoralist community of southern Ethiopia. A mixed follow-up study. *World Psychiatry*, 9, 98–102.
- Shirae, E., & Levy, D. (2007). *Cross-cultural psychology: Critical thinking and contemporary applications*. Boston: Pearson Education Inc.
- Singer, M., Bulled, N., Ostrach, B., & Mendenhall, E. (2017). Syndemics and the biosocial conception of health. *Lancet*, 389: 941-50.
- Skeen, S., Lund, C., Kleintjes, S., & Flisher, A. (2010). Meeting the Millennium Development Goals in Sub-Saharan Africa: What about mental health? *International Review of Psychiatry*, 22(6), 624–631.
- Smith, C. P. (2000). Content analysis and narrative analysis. In H. T. Reis, & C. M. Judd (Eds.), *Handbook of research methods in social and personality psychology* (pp. 313–335). New York: Cambridge University Press.
- Sorsdahl, K. R., Flisher, A. J., Wilson, Z., & Stein, D. J. (2010). Explanatory models of mental disorders and treatment practices among traditional healers in Mpumalanga, South Africa. *African Journal of Psychiatry*, 13, 284–290.
- Spencer, P. (2004). *The Samburu: A study of gerontocracy*. London: Routledge.
- Stites, S., & Akabwai, D. (2010). ‘We are now reduced to women’: Impacts of forced disarmament in Karamoja, Uganda. *Nomadic Peoples*, 14(2), 24–43.
- Stites, S., Akabwai, D., Muzurana, D., & Ateyo, P. (2007). *Angering Akuju: Survival and suffering in Karamoja. A report on livelihoods and human security in the Karamoja region of Uganda*. Boston: Feinstein International Centre, Tufts University.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, California: SAGE Publications, Inc.
- Summerfield, D. (2008). How scientifically valid is the knowledge base of global mental health? *BMJ*, 336, 992–994.
- Summerfield, D. (2012). Afterword: Against “global mental health”. *Transcultural Psychiatry*, 49(3–4), 519–530. doi:10.1177/1363461512454701.
- Sundal, M. (2010). Nowhere to go: Karimojong displacement and forced resettlement. *Nomadic Peoples*, 14(2), 72–86.
- Sundal, M. B. (2009). *Difficult decisions: Karimojong Healing in conflict* (Doctoral dissertation). United States of America, University of Kansas.

- Sundal, M. B. (2012). Not in my hospital: Karimojong indigenous healing and biomedicine. *Journal of Eastern African Studies*, 6(4), 571–590.
doi:10.1080/17531055.2012.708545.
- Swartz, L. (1996). Culture and Mental Health in the Rainbow Nation: Transcultural Psychiatry in a Changing South Africa. *Transcultural psychiatric research review*, 33.
- Swartz, L. (1998). *Culture and mental health: A Southern African view*. Cape Town: Oxford University.
- Swartz, L. (2012). An unruly coming of age: The benefits of discomfort for global mental health. *Transcultural Psychiatry*, 49(3–4), 531–538.
- Swartz, L. (2015a). From Sharpeville to Marikana: The Changing Political Landscape for Mental Health Practice in a Violent South Africa. In: J. Lindert, & I. Levav (Eds.), *Violence and Mental Health* (pp. 381–390). Dordrecht: Springer.
- Swartz, L. (2015b). Thinking about culture and language in psychological research and practice. In: P. Rohleder, & A.C. Lyons (Eds.), *Qualitative research in clinical and health psychology* (pp. 43–56). London: Palgrave Macmillan.
- Szasz, T. (2011). The myth of mental illness: 50 years later. *The Psychiatrist*, 35, 179–182.
- Teuton, J., Bentall, R., & Dowrick, C. (2007). Conceptualizing psychosis in Uganda: The perspective of indigenous and religious healers. *Transcultural Psychiatry*, 44(1), 79–114.
- Tew, J. (2011). *Social approaches to mental distress*. Houndmills: Palgrave Macmillan.
- Thornicroft, G. (2007). Most people with mental illness are not treated. *Lancet*, 370, 807–808.
- Tol, W. A., Barbui, C., Galappatti, A., Silove, D., Betancourt, T. S., Souza, R., . . . van Ommeren, M. (2011). Mental health and psychosocial support in humanitarian settings: linking practice and research. *Lancet*, 378, 1581–1591.
- Tomlinson, M., Rudan, I., Saxena, B. S., Swartz, L., Alexander, A., Tsai, A. C., & Patel, V. (2009). Setting priorities for global mental health research. *Bulletin of the World Health Organization*, 87, 438–446.
- Tomlinson, M., Swartz, L., Kruger, L., & Gureje, O. (2007). Manifestations of affective disturbance in sub-Saharan Africa: Key themes. *Journal of Affective Disorders*, 102, 191–198.

- Trotter, R. T., & Schensul, J. J. (1998). Methods in applied anthropology. In H. R. Bernard (Ed.), *Handbook of methods in cultural anthropology* (pp. 691–735). Walnut Creek: Altamira Press.
- Uganda Bureau of Statistics. (2009). *Uganda National Household Survey*. Kampala: UBOS.
- Uganda Bureau of Statistics. (2014). *National Housing and Population Census. Provisional results*. Kampala: UBOS.
- Uganda Bureau of Statistics. (2016). *Uganda Demographic and Health Survey*. Kampala: UBOS.
- Uganda Bureau of Statistics. (2017). *The National Population and Housing Census 2014 – Area Specific Profile Series*. Kampala: UBOS.
- Uganda Bureau of Statistics. (2019). *Statistical abstract*. Kampala: UBOS
- Ulin, P. R., Robinson, E. T., & Tolley, E. E. (2005). *Qualitative methods in public health: A field guide for applied research*. Danvers: Jossey-Bass
- United Nations Development Programme. (2007). *Human Development Report Uganda. Rediscovering agriculture for human development*. Kampala: UNDP.
- United Nations Population Fund. (2018). *Population Matters: Leaving no one behind in Karamoja*. Kampala: UNFPA.
- United Nations Millennium Project. (2005). *Investing in development: A practical plan to achieve the Millennium Development Goals*. New York: Earthscan.
- Van der Geest, S. (2007). Is it possible to understand illness and suffering? *Medische Anthropologie*, 19(1), 9–21.
- van der Merwe, J. C. (2008). The relevance of worldview interpretation to healthcare in South Africa. In T. Falola, & M. M. Heaton (Eds.), *Health knowledge and belief systems in Africa* (pp. 55–66). Durham: Carolina Academic Press.
- van der Watt, A. S. J., Das-Brailsford, P., Mbanga, I., & Seedat, S. (2019). South African isiXhosa traditional healer self-identification, training, practices, and their perceptions of collaboration with medical providers: an exploratory study. *South African Journal of Psychology*, 1 –13. DOI: 10.1177/0081246319856984.
- van Ommeren, M., Morris, J., & Saxena, S. (2008). Social and clinical interventions after conflict or other large disaster. *American Journal of Preventive Medicine*, 25, 284–286.

- van Ommeren, M., Saxena, S., & Saraceno, B. (2005). Mental and social health during and after acute emergencies: emerging consensus? *Bulletin of the World Health Organization*, 83(1), 1–80.
- Ventevogel, P., Jordans, M., Reis, R., & De Jong, J. (2013). Madness or sadness? Local concepts of mental illness in four conflict-affected African communities. *Conflict and Health*, 7(3). doi:10.1186/1752-1505-7-3
- Vigo, D.V, Patel, V, Becker, A et al., (2019). A partnership for transforming mental health globally. *Lancet Psychiatry*, 6: 350-56. doi. org/10.1016/S2215-0366(18)30434-6.
- Ventevogel, P., van Ommeren, M., Schilperoorda, M., & Saxena, S. (2015). Improving mental health care in humanitarian emergencies. *Bull World Health Organ*, 5;93:666–666A. doi.org/10.2471/BLT.15.156919.
- Wainberg, M. L., Scorza, P., Shultz, J. M., Helpman, L., Mootz, J. J., Johnson, K. A., . . . Arbuckle, M. R. (2017). Challenges and opportunities in global mental health: a research-to-practice perspective. *Curr Psychiatry Rep*, 19(5): 28. doi:10.1007/s11920-017-0780-z.
- Wairama, G. B. (2001). *Uganda: The marginalization of minorities. A MRG International report*. London: MRG.
- Wang, P. S., Angermeyer, M. C., Borges, G., Bruffaerts, R., Chiu, W. T., & Girolamo, G. (2007). Delay and failure in treatment seeking after first onset of mental disorders in the World Health Organization’s World Mental Health Survey Initiative. *World Psychiatry*, 6(6), 177–185.
- Weiss, M. G., & Somma, D. (2007). Explanatory models in psychiatry. In D. Bhugra, & K. Bhui (Eds.), *Textbook of cultural psychiatry* (pp. 127–140). Cambridge: Cambridge University Press.
- Whyte, S. (1995). Constructing epilepsy: Images and contexts in East Africa. In B. Ingstad & S. R. Whyte (Eds.), *Disability and culture* (pp. 226–245). Berkeley and Los Angeles: University of California Press.
- Whyte, S. R. (1997). *Questioning misfortune: The pragmatics of uncertainty in eastern Uganda*. Cambridge: Cambridge University Press.
- Wijngaaden, V. (2018). Maasai beadwork has always been modern: An exploration of modernity through artifacts. *Cultural Dynamics*, 1–18. doi:10.1177/0921374018809733

- Wiley, A. S., & Allen, J. S. (2009). *Medical anthropology: A biocultural approach*. Oxford: Oxford University Press.
- Williamson, J., & Robinson, M. (2006). Psychological interventions, or integrated programming for well-being. *Intervention*, 4(1), 4–25.
- Winkler, A. S., Mayer, M., Schnaitmann, S., Ombay, M., Mathias, B., Schmutzhard, E., & Jilek-Aall, L. (2010). Belief systems of epilepsy and attitudes toward people living with epilepsy in a rural community of northern Tanzania. *Epilepsy & Behavior*, 19, 595–601. doi:10.1016/j.yebeh.2010.09.023
- World Health Organization. (1992). *International Classification of Diseases* (10th ed.). Geneva: WHO.
- World Health Organization. (2001). *The world health report 2001: New understanding, new hope*. Geneva: WHO
- World Health Organization. (2002). *WHO Traditional Medicine Strategy 2002–2005*. Geneva: WHO.
- World Health Organization. (2003). *Investing in mental health*. Geneva: WHO.
- World Health Organization. (2005). *Mental health atlas*. Geneva: WHO.
- World Health Organization. (2007a). *Saving lives and reducing disease burden due to emergencies: taking stock of WHO's work in crises in Uganda. Health action in crisis (HAC) programme. Annual report*. Kampala: WHO.
- World Health Organization. (2007b). *International Classification of Diseases* (10th ed.). Geneva: WHO.
- World Health Organization. (2008). *Integrating mental health into primary care: A global perspective*. Geneva: WHO.
- World Health Organization. (2009). *Mental health, poverty and development. Discussion paper*. Geneva: WHO.
- World Health Organization. (2011). *Mental health atlas*. Geneva: WHO.
- World Health Organization. (2013). *Building back better: sustainable mental healthcare after emergencies*. Geneva: WHO.
- World Health Organization. (2015). *Health in 2015: from MDGs, Millennium Development Goals to SDGs, Sustainable Development Goals*. Geneva: WHO.
- World Health Organization. (2013). *Building back better: sustainable mental healthcare after emergencies*. Geneva: WHO.
- World Health Organization. (2014). *Mental health atlas*. Geneva: WHO.

World Health Organization. (2017). *Mental health atlas*. Geneva: WHO.

World Health Organization. (2019). *Making the Investment Case for Mental Health: A WHO/UNDP Methodological Guidance Note*. Geneva: WHO.

Zinsstag, J., Ould Tabel, M., & Craig, P. S. (2006). Editorial: Health of nomadic pastoralists: new approaches towards equity effectiveness. *Tropical Medicine and International Health*, 11(5), 565–568. doi:10.1111/j.1365-3156.2006.01615.x

Appendix 1: Informed Consent Form for (adult) Study Participants

PARTICIPANT LEAFLET AND CONSENT FORM

ETHICS REFERENCE NO: N10/05/180

Mental illness and health-seeking of adults and children: a critical ethnography of Karamoja, North-Eastern Uganda.

Principal Investigators:

- 1) James Wasike Mangeni Byanasaye, PhD candidate, Department of Psychology, University of Stellenbosch, South Africa.
- 2) Prof Mark Tomlinson, Department of Psychology, University of Stellenbosch, South Africa.

**CONTACT NUMBER: +256 -414 540 650 (OFFICE); +256-782 330 278 (CELL)
021- 8083446 (OFFICE); 083-3014868 (CELL)**

You are being invited to take part in this research project. Please take some time to read the information on this form, which will explain the details of the project. Please ask the study team any questions about the research project that you do not fully understand. It is very important that you understand what the research is about and how you can be involved. Also, whether you choose to participate in this study or not is completely up to you. No one is forcing you to take part. If you say no, this will not affect you negatively in any way whatsoever. You are also free to change your mind at any point, even if you agree to take part in the beginning.

This research has been approved by the **Human Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki (October 2008) and the National research guidelines of the **Uganda National Council for Science and Technology (UNCST)**.

What is the research study all about?

This study will be conducted in Karamoja, North-Eastern Uganda. Both adults and children (8-12 and 13-15 years old respectively) will participate in this study and the information from this study will be used for the purpose for writing a doctoral thesis, which will be examined at Stellenbosch University. Stellenbosch University is paying for the study with supplementary funding from Makerere University.

What are trying to do?

This is a study which is trying to understand local conceptions of mental illness and health-seeking of adults and children in Karamoja with the aim of helping policy makers and health professionals design and provide culture sensitive and appropriate interventions in order to improve mental healthcare in Karamoja. The researchers will share the findings of the study with the above mentioned stakeholders, including local community members during the de-brief meetings that will be organised in the study community in Uganda.

What will the study involve?

We will be conducting two sessions of talks (interviews) with you and 8 group conversations (focus groups) with groups of individuals in the community. The exercise will involve asking short questions regarding local understanding of mental illness and its interpretation, and the actions people take to manage mental illness in this community. The data collection will take place at your home or any

other such meeting place/venue arranged for the group discussions. Each session of interview with you (personal interview) will take between 30 and 40 minutes while the group discussion will last about 1 hour.

Recording

We would like to audio-record the interviews in order to have a clear understanding of the talks and conversations. The audio- recordings will be confidential and safely kept for the entire duration of the research. After the tapes have been listened to, they will be destroyed.

Why have you been invited to participate?

We have asked you to be involved in this study because we would like to learn from your knowledge and experience of the local conditions that affect mental health and wellness in this community.

Will you benefit from taking part in this research?

The research may well reap benefits for how to care for adults and children who suffer mental health problems in the future.

Are there risks involved in you taking part in this research?

The research involves you talking to the research team at your convenience. No harm will come to you through participating in this study. If you become upset by any of the questions asked of you, feel free to talk to the researchers.

If you do not agree to take part, what alternatives do you have?

You do not have to take part in this research and, if you decide not to, this will not affect you or your family at all.

Who will have access to your information?

All the data will be stored safely and kept in strict confidence by the members of the research team. If this is published in a journal, all participants and places will remain anonymous.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in this study, but you will be given a token for transport refund and refreshment and children will receive a small gift.

Is there anything else that you should know or do?

You can contact Mr. James Wasike at tel +256 414- 540 650 (office) or +256 782- 330 278 (cell)
You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I.....agree to take part in a research study entitled

(Mental illness and health-seeking of adults and children: a critical ethnography of Karamoja, North-Eastern Uganda).

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressured to take part.

- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (*place*).....on (*date*).....2010

.....

Signature of participant

Declaration by investigator

I (*name*).....declare that:

- I explained the information in this document to.....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that s/he adequately understands all aspects of the research, as discussed above.

Signed at (*place*).....on (*date*).....2010

.....

Signature of investigator

Appendix 2: Informed Consent Form for (child) Study Participants

PARTICIPANT LEAFLET AND CONSENT FORM

ETHICS REFERENCE NO: N10/05/180

Mental illness and health-seeking of adults and children: a critical ethnography of Karamoja, North-Eastern Uganda.

Principal Investigators:

- 1) James Wasike Mangeni Byanasaye, PhD candidate, Department of Psychology, University of Stellenbosch, South Africa.
- 2) Prof Mark Tomlinson, Department of Psychology, University of Stellenbosch, South Africa.

CONTACT NUMBER: +256 -414 540 650 (OFFICE); +256-782 330 278 (CELL)
021- 8083446 (OFFICE); 083-3014868 (CELL)

Your child is being invited to take part in this research project. Please take some time to read the information on this form, which will explain the details of the project. Please ask the study team any questions about the research project that you do not fully understand. It is very important that you (and your child) understand what the research is about and how your child can be involved. Also, whether you agree to allow your child to participate in this study or not is completely up to you (and your child). No one is forcing your child to take part. If you say no, this will not affect your child negatively in any way whatsoever. You are also free to change your mind at any point, even if you agree to allow your child to take part in the beginning.

This research has been approved by the **Human Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki (October 2008) and the National research guidelines of the **Uganda National Council for Science and Technology (UNCST)**.

What is the research study all about?

This study will be conducted in Karamoja, North-Eastern Uganda. Both adults and children (8-12 and 13-15 years old respectively) will participate in this study and the information from this study will be used for the purpose for writing a doctoral thesis, which will be examined at Stellenbosch University. Stellenbosch University is paying for the study with supplementary funding from Makerere University.

What are trying to do?

This is a study which is trying to understand local conceptions of mental illness and health-seeking of adults and children in Karamoja with the aim of helping policy makers and health professionals design and provide culture sensitive and appropriate interventions in order to improve mental healthcare in Karamoja. The researchers will share the findings of the study with the above mentioned stakeholders, including members of your local community during the de-brief meetings that will be organised in the study community in Uganda.

What will the study involve?

We will be conducting two sessions of talks (interviews) with your child and group conversations (focus groups) with 2 groups of children in this community. The exercise will involve asking your child short questions regarding what s/he sees, say and how s/he feels and thinks about mental illness in this community. The data collection will take place at your home or any other such meeting place/venue arranged for the group discussions with children. Each session of interview or discussion with your child will last between 20 and 40 minutes.

Recording

We would like to audio-record the interviews in order to have a clear understanding of the talks and conversations with the children. The audio- recordings will be confidential and safely kept for the entire duration of the research. After the tapes have been listened to, they will be destroyed.

Why have you (and your child) been invited to participate?

- A. We have asked your child to be involved in this study because we would like to learn from her/his knowledge and experience of the local conditions that affect mental health and wellness in this community.

Will you (and your child) benefit from taking part in this research?

The research may well reap benefits for how to care for adults and children who suffer mental health problems in the future.

Are there risks involved in you (and your child) taking part in this research?

The research involves your child talking to the researcher(s) at her/his convenience. No harm will come to your child through participating in this study. If the child becomes upset by any of the questions asked of her/him, s/he should feel free to talk to the researcher(s).

If you (and your child) do not agree to take part, what alternatives do you have?

You (and your child) do not have to take part in this research and, if you decide not to, this will not affect you or your family at all.

Who will have access to your information?

All the data will be stored safely and kept in strict confidence by the members of the research team. If this is published in a journal, all participants and places will remain anonymous.

Will you (and your child) be paid to take part in this study and are there any costs involved?

No, you (and your child) will not be paid to take part in this study; the child will receive a small gift.

Is there anything else that you should know or do?

You can contact Mr. James Wasike at tel +256 414- 540 650 (office) or +256 782- 330 278 (cell)
You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I (and my child).....agree to take part in a research study entitled

(Mental illness and health-seeking of adults and children: a critical ethnography of Karamoja, North-Eastern Uganda).

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressured to take part.
- I (and my child) may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (*place*).....on (*date*).....2010

.....

Signature of parent/guardian

Declaration by investigator

I (*name*).....declare that:

- I explained the information in this document to.....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that s/he adequately understands all aspects of the research, as discussed above.



Signed at (*place*).....on (*date*).....2010

.....

Signature of investigator

CHILD ASSENT TEMPLATE³³

ETHICS REFERENCE NO: 10/05/180

	<p>STELLENBOSCH UNIVERSITY FACULTY OF HEALTH SCIENCES</p>	
---	---	---

PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM



TITLE OF THE RESEARCH PROJECT: Mental illness and health-seeking of adults and children: a critical ethnography of Karamoja, North-Eastern Uganda.

RESEARCHERS NAME(S):

- 1) James Wasike Mangeni.B
- 2) Prof Mark Tomlinson

ADDRESS: Department of Psychology, Stellenbosch University, South Africa

CONTACT NUMBER: CONTACT NUMBER: +256 -414 540 650 (OFFICE);

+256-782 330 278 (CELL)

021- 8083446 (OFFICE); 083-3014868 (CELL)

What is RESEARCH?

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about disease or illness. Research also helps us to find better ways of helping, or treating children who are sick.

What is this research project all about?

This research project is about people (both adults and children) whose behaviour or actions are so strange because they are sick or suffering. Such people may also need help i.e., treatment and the support of their family members and friends.

Why have I been invited to take part in this research project?

So that I can give my views about what I see, feel and know as examples of strange behaviour and actions because of sickness and suffering by some people in my community. I can also tell how they get help e.g., treatment and suggest better ways in which they can be helped.

³³ With thanks to Anel Kirsten for graphics and layout.

Who is doing the research?

My name is James Wasike. I am a student at the University. I would like to understand from children what they see, feel, think and understand strange behaviours and actions by some people in their community. I would also like to know from children how such people normally get help in the community.

What will happen to me in this study?

I will talk about what I see, feel, think and know as strange behaviours and actions by some people in my community. I will also explain how such people get help e.g., treatment in case I know.

Can anything bad happen to me?

Nothing bad will happen to you. The talk will take about 20 -30 minutes so that you don't get tired. Also feel free to tell me those things that may make you feel bad such that we talk about them. Please tell your parents if you feel bad or unhappy when I talk to you.

Can anything good happen to me?

Yes, by helping to suggest how people who behave and act in a strange way can get help, such people can be helped in a better way in my community.

Will anyone know I am in the study?

No one will know you are in the study because your name or that of anyone in your family will not be written anywhere. I am only interested in what you will tell me.



Who can I talk to about the study?

In case you have questions or get any problems because of the things we shall talk about, contact me (James Wasike). My tel. 0414- 540 650 (office) 0783- 330 278 (cell)

What if I do not want to do this?

You do not have to answer questions and, if you decide not to, nothing bad will happen to you or your family. You can choose to stop taking part in the talks at any time and you will not be punished in any way.

Do you understand this research study and are you willing to take part in it?

YES

NO

Has the researcher answered all your questions?

YES

NO

Do you understand that you can pull out of the study at any time?

YES

NO

Signature of Child

Date

Appendix 3: In-depth interview guide (Adults)

- 1) What is the meaning of mental illness? (*probe for local understanding of the nature of mental illness in Karamoja*)
- 2) What shows that a person has problems of thinking, feeling and acting?
- 3) In what different forms does mental illness occur? (*probe for types & local names*)
- 4) What is the meaning of each type of mental illness? (*probe the reasons for naming*)
- 5) For each type of mental illness named, how do you tell a person who has got it? [*probe for symptoms (body pains, feelings & thoughts) and behaviours (actions)*]
- 6) What are the causes of each type of mental illness you have mentioned? (*Draw a matrix showing type of mental illness by perceived causes*)
- 7) Why do you think the causes mentioned in 6 above bring mental illness? (*probe for reasons*)
- 8) How does each type of mental illness start? (*probe for origin and onset*)
- 9) What types of mental illness commonly affect a) men b) women and c) children? (*probe for reasons Why*)
- 10) How do the structural problems in Karamoja (e.g. hunger, poverty, diseases, insecurity, cattle raids and military disarmament) cause mental illness among the people? (*Draw matrix showing structural problem by type of mental illness and reasons Why*)
- 11) What are the common complaints the Karimojong use when they want to express and communicate feelings of emotional distress and psychological problems? (*probe for local expressions used for specific types of emotional distress*)
- 12) Which of those complaints above are commonly used by women and men? (*probe for the meaning of each local expression*)
- 13) What do people think of mad adults (men and women)? (*for each type of mental illness probe for attitudes and beliefs and reasons Why*)
- 14) What do people think of children with mental illness? (*probe for attitudes and beliefs and reasons Why*)
- 15) What do people think of a family with a mad person? (*probe for attitudes and beliefs and reasons Why*)
- 16) How are the different types of mental illness perceived in terms of outcome or effects?
- 17) How does mental illness affect a person's life and future (*probe for consequences of mental illness*)?
- 18) What are the common fears or phobias adults complain of most that show poor health in Karamoja? (*probe by gender and reasons Why*)
- 19) How do the Karimojong treat mental illness? (*probe by type of mental illness and reasons for the choice of treatment e.g. traditional and bio-medical*)

- 20) What types of mental illness are treated by hospitals? (*probe for reasons Why*)
- 21) What types of mental illness are treated traditionally (*probe for reasons Why*)
- 22) What traditional rituals are used to treat mental illness (*probe for the names of specific rituals and how they are carried out*)
- 23) How effective is bio-medical care in curing mental illness (*probe for types of mental illness and reasons Why*)
- 24) How effective is traditional healing in curing mental illness (*probe for types of mental illness and reasons Why*)
- 25) How do the Karimojong treat children with mental illness? (*probe for type of mental illness and form of treatment e.g. traditional or bio-medical and reasons Why*)
- 26) What other illnesses are believed to affect people's minds or spirits?
- 27) How do people in Karamoja perceive suicide?
- 28) What is the meaning of suicide? (*probe for its local interpretation*)
- 29) What factors drive people to commit suicide in Karamoja?
- 30) What forms does it take? (probe for means people use to commit suicide)
- 31) Who is most affected by gender and age? (*probe for reasons Why*)
- 32) How do the Karimojong respond to an act of suicide? (probe for cultural rituals carried out, their names and the meaning attached to each)
- 33) In your opinion, how is suicide related to mental illness? (*probe for reason Why*)

Record the informant's gender, date of interview and length (hours) of interview

Appendix 4: Interview Guide for Children

a) Interview guide for children

I will briefly introduce/explain what the talk/conversation is about to my child informants.

- Socio-demographics
 - Age
 - Sex
 - Level of schooling
 - Number of siblings
 - Occupation of parents/caregivers e.g. main source of income
 - Type of housing
- Ideas, feelings/experiences of mental illness
 - What do you think is strange behaviour?
 - Could you tell me how you call people with strange behaviour?
 - What do you think they are suffering from?
 - If mental illness, what makes you to think so?
 - Is mental illness different from other illnesses?
 - What do you think causes mental illness?
 - Do you think children suffer from mental illness?
 - How can you describe your feelings about mental illness?
 - Do children who suffer mental illness get help in this community?
 - How children suffering from mental illness treated in this community?
 - How would you describe life of children suffering from mental illness?
 - How can mental illness be prevented?
- Livelihood activities and social relationships within household
 - What kind of tasks do children do in the household?
 - Do children (boys/girls) do the same tasks? If not, what do they do?
 - What role (s) do children take in household decision making to allocate tasks?
 - What role (s) do children take in the household because their sibling and or, parent/guardian suffers from mental illness?
 - What are those things that children are not allowed to do if they are suffering from mental illness?
 - When children suffer mental illness, how their relationship with parents/guardians or siblings change [if any] in the household?

Appendix 5: Research clearance #2389



Uganda National Council For Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Your ref:
SS 2389

Date : 27/10/2010..

Our ref:

Mr. James Wasike Mangeni
Department of Sociology
Makerere University
P.O Box 7062
Kampala

Déar Mr. Wasike,

RE: RESEARCH PROJECT, "MENTAL ILLNESS AND HEALTH SEEKING OF ADULTS AND CHILDREN: A CRITICAL ETHNOGRAPHY OF KARAMOJA, NORTH-EASTERN UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **July 29, 2010**. The approval will expire on **May 29, 2011**. If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,


Leah Nawegulo
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

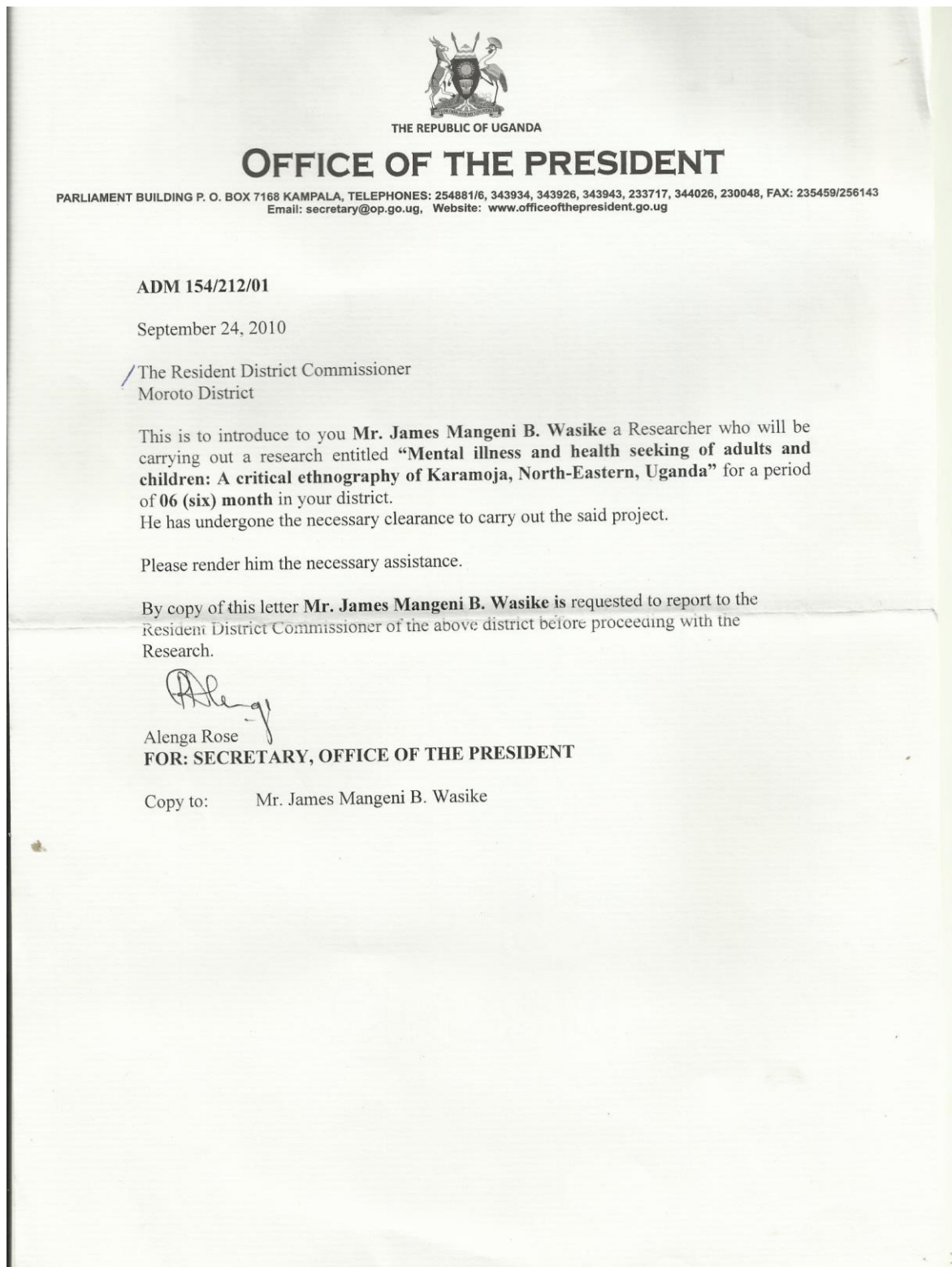
LOCATION / CORRESPONDENCE

Plot 315/7, Nasser Road
P.O. Box 6884
Kampala, Uganda

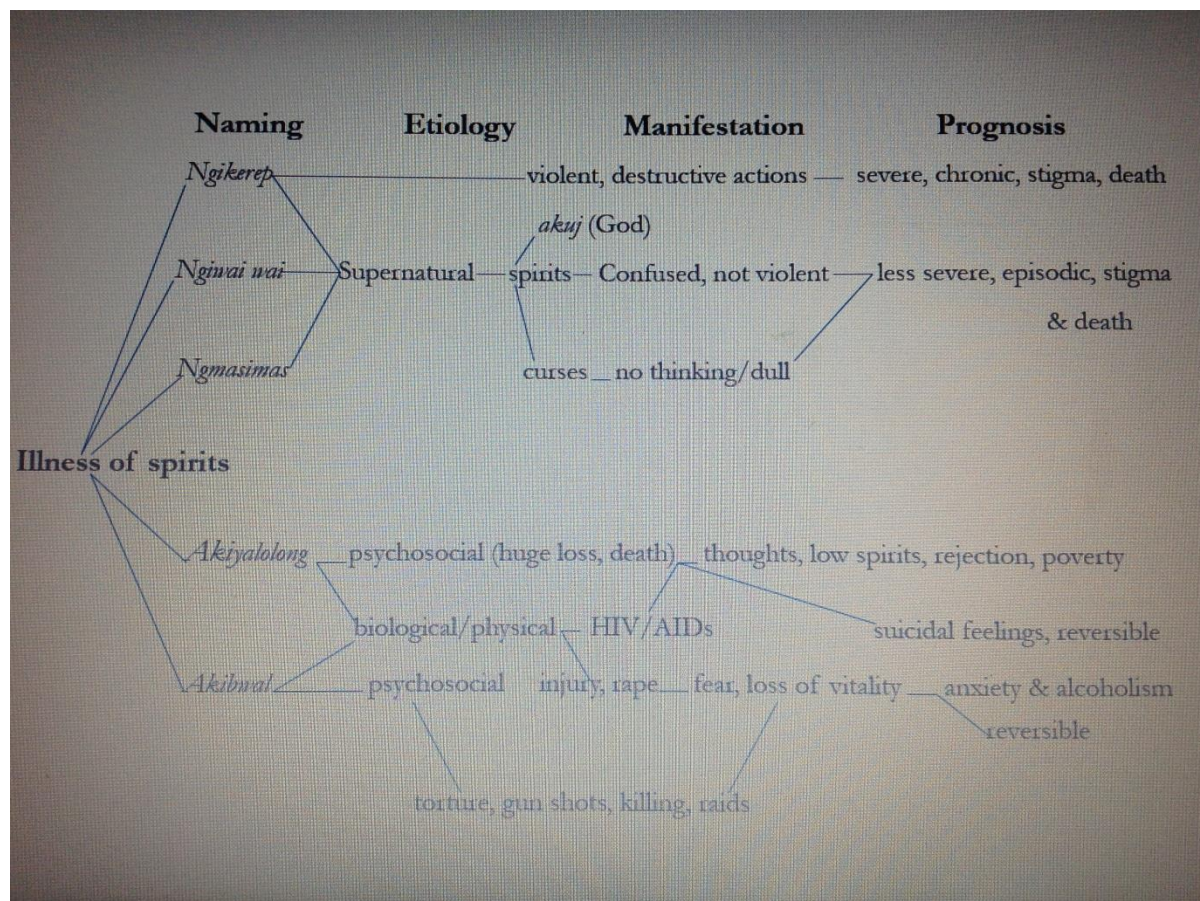
COMMUNICATION

TEL: (256) 414-250 499, (256) 414 705 500
FAX: (256) 414-234 579
EMAIL: uncst@starcom.co.ug
WEBSITE: <http://www.uncst.go.ug>

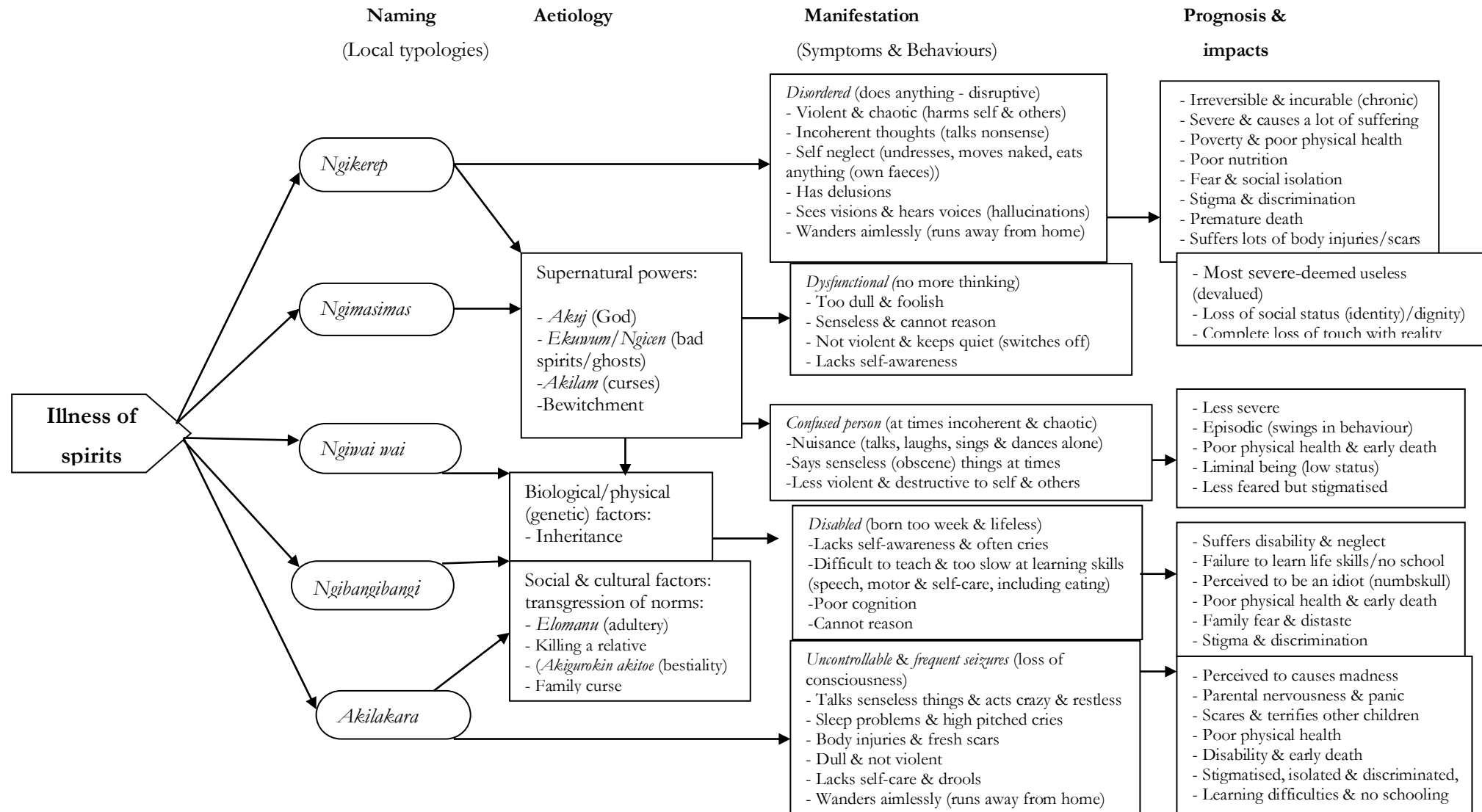
Appendix 6: Research clearance ADM 154/212/01



Appendix 7: Summary thematic network for conceptualisations of mental illness



Appendix 8: Detailed Thematic network for lay conceptualisations of mental illness (Perceived psychotic problems)



Appendix 9: Thematic network – health-seeking for severe mental illness

